Be Not Afraid

written by
Lindy S. Johnson
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Addendum and Postcripted
2012

Foreward

Before turning the pages of this book, an introduction to the storyteller is necessary. It is not an easy task to describe myself objectively and I will admit that the cursor sat there blinking at me for quite some time. While it is easy to stick to the chronological facts of what has happened in my life and identify the other important players, these things only tell a small part of the story. So, I will begin with the hardest part first and then go on to these other things. Notwithstanding the difficulties I faced that will unfold in the pages to follow, I am generally an upbeat and positive person. I am quick to smile and love to laugh. Although most would assume that I am an extrovert who loves being with people, I actually draw my energy from within or in the close company of only one or two people at a time.

Many, in particular those with whom I work, would probably call me more than a bit stubborn, intense, and even impatient. If I believe in something strongly, I will not let go. I don't live in the calm world of mediocrity, but tend toward the extremes through exaggeration and storytelling, and by staking out my ardent belief in certain—and to me very important—causes. Luckily, I seem to have a bottomless well of energy to grab a hold of life and live it in my own vibrant way.

My greatest love, not including—of course—the people in my life, is to be outdoors. This love was instilled at a very early age with Mom often admonishing us, "get outside!" and from both my parents doing such things as lying with us on our backs identifying things in the shapes of clouds. I love to hike, backpack, bicycle, and sea kayak. I have my camping gear ready to go upon short notice and my Toyota pickup is easily loaded with any one of my three sea kayaks. All of my outdoor interests serve as a

means to be among the trees listening to the wind running through the branches; delight in wild creatures, whether they be moose, dolphins, herons, or ospreys; and listen to crashing waves.

I have always divided the people who like to do outdoor activities into two categories: those who like to do the "fast" and, to me, dangerous things like racing bicycles, downhill skiing, and whitewater kayaking and those who would rather lollygag along on a touring bike, cross country skis, or paddling a sea kayak. Even in this latter category, I am on the slow end of doing things and am not in a hurry to get anywhere when I play. Speed is not important to me and, in fact, I actually avoid sports where it is a prerequisite. This is not to say, however, that I haven't done things that have caused eyebrows to lift and people to wonder at my sanity. One of these things, which ranks among my favorite vacations of all times, was my solo bicycle trip from the Grand Tetons in Wyoming to the Grand Canyon in Arizona; I crossed the Continental Divide 11 times and thoroughly enjoyed each and every day. It was a chance to be outside for over five weeks, with very little stuff to weigh me down. Now, living in a city and working a "normal" job, my time outdoors is necessarily confined to vacations, weekend camping trips, kayaking, and my backyard.

My soul is also called unceasingly toward yoga and meditation. It isn't just the flexibility that yoga brings that draws me to it, but the incredible mind, body, spirit connection that it instills. I search for yoga classes that have these three elements as their foundation and are not simply serving as work out routines.[1] As for meditation, I was at first unsure how to dive into it. I read books and then assiduously tried to sit still,

[1] A wonderful yoga study that satisfies this need is Sun & Moon Studio in Arlington, VA. See www.sunandmoonstudio.com.

but my mind remained unruly and an itch always persisted the minute I sat down and closed my eyes. Lucky for me, I began to see an acupuncturist, Erica Lazaro, who introduced me to an entirely new world in Washington, D.C. At her suggestion, I began to attend Friday morning meditations with Rudy and Sharon Bauer at the Washington Center for Consciousness Studies.[2] Little did I know that yoga would play a key role in saving my life and that it, and my meditation practice, would be crucial in helping me through such a difficult period in my life.

In the pages that follow, it will become quite apparent that I have an absolutely wonderful family and group of friends, who I call my "family of friends." To know me is to know my family and I am fortunate that they are among my best friends. My parents are 30 years older than me and yet, even when I am in perfect health, they tire me out with their energy. They are extremely resourceful and there is little that they cannot do to turn a house into a beautiful home. They instilled in me a staunch sense of independence (which took a beating on this cancer journey), an upbeat attitude, a strong sense of right and wrong, and an understanding of the right way to treat other people.

I have three amazing siblings. My oldest sister, Denise or "Nesa" to me, is almost six years older than me and lives in Atlanta. She has a heart as big as the ocean and is trying to eradicate polio from this planet. She too is a bundle of energy and facilitates and eases my life immeasurably. She, along with Mom, is my kayaking and backpacking buddy, and maintains close contact with each one of us in the family. Bob, my brother, is married to Melani; they have three kids and live in Pensacola, Florida. Bob can—and will—talk to anyone, no matter what their station is in life. His pleasures are simple: his family, fishing, coaching, and hanging out. His very manner of speech is

[2] See www.consciousnessandmeditation.com/ for more information on this wonderful place.

funny, without him ever intending it to be so! Katrina, or Trina-pie, is married to Mike; they have four kids and, after living in Spain for over eight years, they returned to the States and now live in Montana. Trina loves to have fun. Her laughter is loud and long, and she often leaves people smiling and shaking their heads at her energy. She has incredible artistic talent which has lately found its expression in beautiful quilts.

My family of friends consists of an eclectic group of people. They range from a friend I've had since babyhood, to those I met throughout the various stages in my life, to those who share my passion for yoga and meditation, to those I have the good fortune to work with, to extended members of my family, to people I met while overseas. All these people, upon hearing the news of my cancer diagnosis, circled me with love and support. Even now, I remain overwhelmed and humbled by people's reactions.

There is one last piece of the puzzle that is an important part of my life. I have an absolute passion for the oceans and protecting them. Therefore, I am most fortunate to work for the National Oceanic & Atmospheric Administration (NOAA) in the General Counsel's Office of International Law. My entire educational training led me to this job, from James Madison College at Michigan State University where I focused unrelentingly on issues pertaining to the United Nations Convention on the Law of the Sea, to my Masters of Science degree from London School of Economics in Sea-Use Law, to my law degree from Tulane Law School where I took classes in admiralty law and law of the sea. I still find it hard at times to believe that I actually get paid to work on issues I love!

Finally, there are the objective things that are easy to relate. I was born and raised in Hartland, Michigan. I have lived in six states (Michigan, Wyoming where I worked for the National Park Service during college summers, Louisiana for law school,

California where I clerked for a judge after law school, New York where I worked for the law firm of Cleary, Gottlieb, Steen & Hamilton, and Virginia where I now reside) and two places outside the United States (Paris, France, and London, England). I am not married and, although I adore my siblings' and friends' kids, I have no children. I love to learn and have a passion for traveling.

ADDENDUM February 2012

Lindy and I were married June 26th, 2009 in the Grand Teton's National Park and made our home in Alexandria, Virginia. Lindy passed away at our home in the loving care of mother, Tootie Johnson, of Hartland, MI, sister, Denise Johnson, of Hartland, MI, and husband, David Beddoe, of Virginia and many many dear family (father, Richard (Dick), brother Bob, and sister Trina and her family, and friends who stood by Lindy in her battle with colon cancer, in the last 18 months of oncology, palliative, and hospice care, giving so much love and support.

Her last correspondence to complete this journey is added by her loving puzzle-piece husband at the end of the story.

Who, Me?

"Anyone can have a good day. The question is what do you do on a bad day. That's when you're being tested. In a very tangible sense, a bad day shows your innermost essence more than a good day."

Arthur Golden, author[3]

At the end of a long nondescript hallway, the phone almost seemed to fade into the wall and yet, it riveted my attention. Everything seemed to move in slow motion around me. The sounds of the waiting room were suddenly muted and then buzzed in the background after the sonogram technician sympathetically told me that my gynecologist was waiting for me on the phone. The hallway to it seemed like a million miles long. How could this day have gone so wrong? It was my 44th birthday. I always take the day of my birthday off from work and do something fun. Today, however, I had decided to kill two birds with one stone and get this visit to my gyno over with. I knew that she was going to tell me that the small bulge on my stomach was simply a fibroid… . My mind drifted, what was it with that saying about the two birds? Why would anyone want to kill even one bird with a stone let alone two? I reached for the phone, knowing what was to come just by the way the technician had approached me: "I'm sorry Lindy, but it looks like you have cancer."

I hung up the phone and just stood there, unsure of what to do. I thought I should cry and even tried to, but no tears came. My hand automatically reached for the phone again to call my Mom, but I stopped when it occurred to me that perhaps I shouldn't tie

[3] Many of these wonderful quotations at the beginning of each chapter were sent as part of a list serve developed by Dr. Randy Watson. Through this free list serve, Randy sends out inspirational quotes and stories that help lift the spirits and motivate people to reach for their dreams. They definitely provided welcomed relief and strengthened my resolve through this difficult time in my life. My favorite quotation is the one with which he ends each email: "Live with Passion!" To subscribe, send him an email at randy.wilson@mcpherson.com.

up that particular phone. I left the doctor's office, which was busy with another day of people coming and going, phones ringing, computers humming and life going on as normal. For me, however, while everything looked the same, life had changed in a few short hours. I had cancer.

On my way out of the building, I passed a pay phone and once again started to dial Mom. Moms are always among the first people we want to talk to when we are sick. I knew too that she would be able to give me comfort and strength, tell me that things weren't so bad, and help me figure out how I was supposed to react to this news. I had the number half dialed when I stopped again. What if I fell apart talking to her? Here I was in a sterile office building, with no one I knew anywhere near me. How could I drive if I was crying? No, I wanted to be home where I felt safe before I told anyone. As I drove home, time seemed suspended. I kept going back through the morning's events and to that final news, but my mind would flit quickly away from it. So, I settled on thinking about my biggest concern. How could I turn this day around and what was I going to do for fun? After all, it was still my birthday!

No one knows how they are going to react when they are told that they have a life threatening disease or how they will behave while they are dealing with it. We can only hope that we will live in a manner that is in accordance with our value system and beliefs, and is true to our very being. If, of course, we haven't taken the time to figure out what these things are, being delivered such news and living through its aftermath will force us to confront such issues directly and continually. The people and things that are important to us become clear, as does the way we behave day to day and the attitude we take towards life. After all, having a life threatening disease is like having a huge mirror and

spotlight thrown on your life. And, even as you deal with the day to day difficulties associated with the disease, there is that all important, underlying question of whether you like what you see in the mirror.

I had never taken the time to learn anything about cancer. Like many people, whenever I heard someone had cancer, I was immediately concerned and thought that it was a sure death sentence…it was just a matter of time. Of course, I had heard the words "remission" and "chemotherapy," but I didn't really understand them nor did they change my belief that a person with cancer would still die from it. I thought that all cancers were the same, with the same treatments and same side effects; the only difference I had ever vaguely focused on was whether it was Stage I, II, III, or IV. I knew that Stage IV was really bad and that a person with Stage I would, of course, live longer, but still eventually die from the disease.

There have been so many things to learn and work through on my journey into the cancer world, so many things to face, deal with, and let go. For instance, if someone had told me that one of the biggest concerns that consumes a cancer patient is "bathroom issues" (*i.e.*, constipation followed by "fire diarrhea"), I would have been skeptical. I have also learned that everyone has cancer cells existing in their bodies and that the word "cancer" is simply a catchall phrase pertaining to when these cells go crazy, start overproducing and attacking various organs of the body. Strangely enough, even if a person has cancer in multiple places—like I did—it is generally the same type of cancer, depending on where the cells originate. For me, it was colon cancer even though it appeared in my ovaries, my bladder, and other spots. Not all cancers are the same and the drugs and treatments, as well as their associated side effects vary. I didn't lose my

hair and I didn't really look that much different from normal throughout the grueling chemo regime.

I had also mistakenly believed that all cancer is treated with chemotherapy. However, if the cancer is localized, chemo may not be necessary and the trouble spot can be treated by radiation. Radiation, of course, has its own associated side effects. Fortunately for me, since my surgeon was able to remove all the tumors, I was not subject to radiation. Unfortunately for me, the cancer cells in my body were still having a party and overproducing. Therefore, chemotherapy was necessary to kill off these rapidly producing new cells and prevent the growth of additional tumors. Since the drugs used in chemotherapy cannot differentiate among the types of cells the body produces, they also kill the new growth of healthy cells. This effect thus results in noticeable (although minor in the scheme of things!) changes in such things as fingernails and hair. More worrisome for a cancer patient is that chemo also kills the new cells necessary to fight off illnesses such as colds or infections. I was therefore lucky that my treatments occurred during the summer!

As for the stages of cancer, well, yes, it is better to have Stage I than Stage IV; however, I no longer believe that everyone with cancer has to die from it. There are a lot of things that play into the outcome. One of the most important assets I had in my fight was a very thorough, wonderful surgeon and an absolutely fabulous oncologist.[4] Without them, I have no doubt that I wouldn't be here. To ensure that they have job satisfaction and as a living advertisement for them, I plan to live a wonderfully full and long life.

[4] My oncologist is Doctor Mary J. Wilkinson, M.D., Medical Oncology & Hematology Associates of Northern Virginia, 8501 Arlington Blvd, Suite 340, Fairfax, VA 22031 (703)207-0733 and my surgeon is Dr. Hans Krebs, M.D., 3289 Woodburn Rd, Suite 320, Annandale, VA 22003 (703)698-7100.

The other critical asset I have is a truly incredible network of family and friends, who supported me through each day and even made life fun during this difficult time. Upon hearing my diagnosis, people encircled me with love. My sister, Denise (Nesa), immediately flew in from Atlanta to accompany me to my first visit to the oncologist. My parents soon followed. The most difficult thing I have ever done is to watch my parents' kind and laugh-lined faces as they listened to the nurse detail all the possible side effects of the chemo. No parent should ever have to hear such news and, even though crying inside for them, all I could do is maintain a stoic and even humorous attitude throughout the meeting.

It became quite clear that I needed someone to drive me to my treatments and stay with me at least for three to five days of the treatment week. Nesa, with the help of my caring friend Dar, made up a schedule of family and wonderful friends to cover the entire six month period. I cannot imagine how difficult it was for these dear people to sit and watch as I was hooked up to the life saving drugs. The grace they showed made it easy for me to relinquish my fierce independence, accept my vulnerability, and learn that most difficult lesson of graciously accepting—and asking for—help from others.

So, I will happily admit that I was wrong: Having cancer is not necessarily a death sentence and it is not helpful to focus on death and dieing upon hearing that you—or a loved one—has cancer. The focus should be on life and getting through, and learning from, this experience. Each person, of course, has different coping mechanisms to help them.[5] For me, it was writing emails to an ever growing, ever caring group of friends and supporters. The pages that follow are based largely on those emails that

[5] One of my dear NOAA friends dealt with breast cancer by crocheting the most beautiful hats! Check them out: www.visualizehair.com.

detailed my passage through the cancer world. It is my fervent hope that this story will help you and allay some of the fear and uncertainty that you may be feeling about cancer. Remember, if you or a loved one has cancer, you are not alone in your struggle and you can live through it!

Dad, Nesa, and Mom

The Road Ahead

"If I were asked to give what I consider the single most useful bit of advice for all humanity, it would be this: Expect trouble as an inevitable part of life, and when it comes, hold your head high. Look it squarely in the eye, and say, 'I will be bigger than you. You cannot defeat me.'"

Ann Landers

Hi everyone! I'll bet you are surprised to see an email popping up from me. My wonderful boss and friend, Karen, and my sister have been great about sending out updates about my health. Today, however, since I am getting stronger after the surgery, I thought I'd send one myself.

First and foremost, I cannot thank you all enough for the cards, gifts, letters, emails, and overwhelming support through this time of unbelievable surprise. The support I've received from all of you and indeed from around the world is truly humbling. It has helped keep my spirit strong, my sense of humor intact, and be able to face doctor after doctor and procedure after procedure--*thank you so much*.

As you have probably heard, although the diagnosis was initially ovarian cancer, they now think it started in the colon and therefore, it is Stage IV colon cancer. I was not initially happy that I had tumors in my ovaries; however, I am now looking at that fact as extremely good news and a gift of life. These tumors caused a small bulge in my lower abdomen and, if it hadn't been for the fact that my cobra and bow yoga poses were becoming increasingly uncomfortable, I would have never gone to the doctor in the first place. (I'd thus encourage you all to start doing yoga!) The only other sign I had that

something may be wrong with my health was that I had a chest cold. As it turned out, my right lung had filled with over eight pounds of fluid because of the tumors.

Things are looking up. The preparation for surgery is over, surgery itself is done and I'm recovering, and I have a great cadre of doctors. I found out late last week that my surgeon was able to remove all of the tumors. Yeah! I wish I could tell you that I did cartwheels, but I was never any good at them anyway.

Even though the tumors are gone, I still have to undergo the dreaded chemotherapy beginning next week. The good news on that front is that there has been a drug approved in the last year with which they have been having fabulous results. So, you see, at least my timing is perfect! Mom, Dad, and I spent three and one half hours at Doctor Mary's office (my oncologist) last week where, after meeting with Doc, her head nurse, Nurse Jen, painstakingly went through all the possible side effects of the chemotherapy treatments. I eventually laid down my pen and stopped taking notes—I looked at her and emphatically stated that I didn't intend on having any of these effects. And that's exactly where I'm going to keep my mind set. Even if I do experience some side effects, my new 24/7 "handlers" (Doc Mary and her wonderful staff) are on call for me, which is another pleasant surprise I've had along the way. (They even love the oceans…)

Doc Mary, my wonderful, control-freak savior!

So, I'm moving ahead day by day. While the cancer has apparently invaded my body (I still maintain to anyone who will listen that I'm insanely healthy), it has not—and will not be allowed to—attack my spirit. I am determined that on the road ahead, the disease will *not* become "the" story of my life, but only a chapter in it. When you see me—which won't be too long in the future I hope—perhaps you can help me with this one. Please don't treat me as a sick person and act as if this is the only thing in my life. However, in saying this, I also don't want any of you to think that you need to tip toe around me and you can ask any question about the cancer that you like. It will undoubtedly be a learning process for us all!

In closing, so many of you have offered your help. Again, I cannot tell you thank you enough. It is not because of my—what did one of you write? headstrong manner (I never thought of that adjective applying to me before!) or independent nature that I am not calling or writing to take you up on these offers. I simply have not walked this road before and I have no idea what to expect, what I will need, or even what I need right

now. All I do know is that I have your cards, your stories, and your good wishes which have been extremely welcome and make me smile.

Before you know it, I'll be back—after all, there are oceans to protect and love, kayaking and yoga to be done, fun to be had, and friends and family to love. Remember, live life large, okay?

Lindy

One of my favorite beaches, Assateague National Seashore.

Milepost 108

"…love the journey, not the destination…"

Anna Quindlen

Hi everyone! Today is such a beautiful day in the Washington D.C. area—it is even more beautiful because for the first time in a very long time, I actually feel great! Before continuing, I must ask that any of you who want to be removed from this email list, please let me know. The decision to send out emails detailing my cancer journey was a difficult one, because in the past I have been intensely private about much of my personal life. Yet, cancer has a way of stripping away certain things. Even more importantly, conversations and correspondence with many of you have revealed that almost everyone has a loved one, a colleague, or someone they know who has had some type of cancer. Some of you are even survivors yourselves. If these emails help any of you understand even a little bit better some of the ins and outs of this disease and what people with cancer face, then perhaps they serve a purpose.

I came to the obvious conclusion last week that cancer is just no fun, but there is hope for the future and even moments of absolute hilarity along the way. If there is any message in this email, that's it.

Last week was my first week to receive chemo. Being me, I wanted to get prepared. Since we all hear that hair loss results from chemo, I decided that this was one thing for which I could prepare—the other things, well, I'd have to take those as they came. So, off we went to what one dear friend told me was the best wig store in the D.C.

area, *Amy's of Denmark*.[6] I was completely unprepared for what happened once we got to the store. I was greeted by a very tall, manly looking woman and, already uncomfortable, my imagination ran wild—was she really a he? Feeling a bit small and vulnerable from surgery, I felt threatened and frankly wanted to run. This, of course, would have violated all my principles of accepting others in all walks of life (and besides Mom was running an errand and had my truck keys). I sat down to wait my turn.

As I overcame my unsettled feelings, I began to look around me. It looked like a regular beauty parlor. There were chairs where you lean back to have your hair washed, two to three stylists were busy with their blow dryers and curling irons, and women were coming and going. And yet, there was something odd. There were no bodies attached to the heads on which the stylists were working! Hair was put on stryofoam heads for the stylists to blow dry and shape. The client with a full head of curlers under the dryer was extremely patient—no complaining (or reading of a magazine) from that head! To wash someone's hair, one stylist simply went to a sink, washed the hair, and then wrung it out.... Mom (since returned with the keys) and I began to laugh.

My turn came. I donned the regular barber's cape and the stylists then brought me wig after wig to try on. As they did so, the women chatted freely with us. I began to realize that they are truly gifted. Over 98% of their clientele have cancer. They know exactly how many days it will take during certain types of chemo before hair falls out and, when it does, how it will happen. (Lucky for me, it is uncertain whether the drugs used for colon cancer will necessarily have this result.) The stylists were incredibly compassionate and helpful in dealing with what is a difficult issue for most women, both

[6] *Amy's of Denmark* is located at 11302 Grandview Avenue,Wheaton, MD 20902 **amyofdenmark@aol.com** (301) 942-3733. I have since learned that this store is extremely well-known and regarded as the place to go if you have cancer and need a wig.

physically and psychologically. I left with a great deal of respect for the women of *Amy's of Denmark*, as well as their hugs and well wishes as I face the days ahead.

Oh, are you wondering whether I bought a wig? Absolutely. It started out looking like a curtain of hair—there was so much hair I couldn't even see out from under it. One of the stylists then proceeded to cut it into a shape around my face; I actually got a hair cut, without getting my hair cut! While I will be quite honest and say that I hope I don't lose my hair so that I need this wig, I had a very rewarding and enriching experience at *Amy's of Denmark.* I'm so glad to know that there are places out there helping people through this disease.

There was one other thing that I desperately wanted to do before chemo started, especially since I didn't know how I would feel throughout the process. I wanted to go paddling. My friend and colleague, David Cottingham ("Cotton") came to my house, loaded my kayaks on top of his van practically with one hand, and off we went. We went to my favorite paddling spot, Pohick Bay, and I watched eagles and ospreys, battled the wind, and thoroughly enjoyed being out on the water. I took a long nap that afternoon and the next day, but at least my spirit was ready to face the drugs.

This is obviously not a picture of me paddling in May, but surprisingly Mom forgot her camera that day and no pictures were taken.

I will not mince words, last week was rather rough. As my good friend Kathy Metcalf's Mom said in a letter, it's hard to imagine (or describe) the aftermath the day of and the days immediately following a treatment. Doc Mary told me this morning that she is going to fix it so that I feel good all the time—I'm definitely counting on it!

My treatments are every other week, two times a week and, hopefully within a six month period, the cancer cells will stop overproducing and return to normal. So on Monday afternoon, Mom and I went to Doc Mary's office. After the usual temperature, blood pressure, and weight check, I was introduced to what I now call the "shot of fire". Being anemic after surgery, Nurse Kristen injected me with red blood cells—fire, going into my arm for 30 seconds.)@(!*#& I was then given three types of drugs, all with their own lovely side effects. They are administered through a medi-port, which was installed the day after surgery. It is in my upper right shoulder and, for a lack of a better way to describe it, it's like an electric socket. Nurse Kristen plugs in a three-quarter inch needle which has a tube attached. The drugs are then fed through it. For those of you

wincing at the thought of the needle, I put a numbing cream on the port one hour before the treatment and thankfully I only feel a slight pressure as the needle goes into the port.

I don't remember much about the treatment on Monday, because Kristen gave me something that caused me to sleep—although I apparently had a nice conversation with Doc Mary. After a two hour infusion of two chemo drugs, I left the office with a small machine that is attached by a tube into the port. It whirs as it feeds me yet a third chemo drug every 20 seconds for the next 46 hours. The queasiness hit that night and the next morning. And then I threw up.

I discovered then and there that I have a trait in common with my doctor—we are both control freaks. She wanted me back in the office as soon as I threw up to make sure that I had enough fluids and that we got on top of this immediately. I balked, getting in my truck was the last thing I wanted to do. So, we negotiated and, instead of going to her Reston office where she was, she let me go to the much closer Fairfax office. Again, more drugs. Whatever they gave me wouldn't allow me to keep my eyes open or my chin off the dashboard on the way home.

Wednesday came with more queasiness, but no vomiting. In the afternoon, we went back to Doc Mary's and Nurse Kristen thankfully removed the box. She then administered a fourth, brand new, cutting edge chemo drug (Avastin) that has been on the market for about a year. Amazingly, I felt much better and I chatted with Mom all the way home.

Nurse Kristen, my guardian angel and from whom "Team Smiley" derived its name.

I'd like to say that I felt great by Thursday, because I expected and wanted to, but I continued to feel the effects of the drugs through Sunday. I hadn't expected that. I have quickly learned, however, that in this fight, there is little I can do to prepare and I have to expect the unexpected. I have to learn to live one day at a time and even sometimes one hour at a time. There have been times in the last four to six days where there was something so painful or so unexpected that I broke down in tears. Lucky for me, these moments were followed by my family and me making jokes and laughing about them, which helped me prepare for whatever came next.

I have learned so much in such a short time. I've learned that no interagency or international meeting—no matter how bad—could have ever prepared me to face this illness (smile), but the lessons that many of you helped me learn are invaluable in dealing with it: perseverance, dogged determination, smiling in the face of adversity, and maintaining hope and belief in the right outcome. Perhaps the most wonderful thing I've discovered is the compassion from all corners—from friends, family, colleagues, and

even complete strangers. It causes me to wonder if it is possible to treat people in this manner even if they don't have cancer and am resolved to try to do so. During the last two days, I have also learned to appreciate deeply feeling great and to enjoy the mundane everyday things that make up my life.

There is no doubt that I will get through this and be a better person in its aftermath. I know that it isn't going to be easy, but with the support, love, and laughter I have surrounding me, I'll be just fine. Thank you all again for the cards, emails, gifts, and unswerving support. And now, thanks for listening,

Lindy

PS If you are wondering about the title of this email, it is simply that any milepost on the road back from cancer is a milestone no matter what its number. I chose 108 for my yoga friends because it is an auspicious number in yogic lore.

Two Worlds

"You should not confuse your career with your life."
Dave Barry

Hi there! I have an amazing announcement: I don't have cancer this week! I feel great and so healthy, that it just doesn't seem possible that I have it. So, I decided that perhaps it is an every other week disease. It is still hard for me to believe the events of the past seven weeks.

Road Trip to Sloan Kettering Memorial Hospital (SK) When the news of my cancer diagnosis erupted, the dad of one of my dearest friends—a doctor himself—advocated strongly that I go to SK for a second opinion. There was a question whether I had ovarian or colon cancer even after six Fairfax Hospital pathologists had agonized over the slides trying to make the correct diagnosis. Since the treatment for the two types of cancer are different, it was critical—especially to my peace of mind—to know. Given that SK is synonymous with cancer research, I knew it was the right thing to do; however, emotionally, it was difficult. I was nervous about second guessing my own doctor (she actually welcomed it, which says volumes about her) and, having lived in New York for three years and commuted back there on weekends for four years afterwards, emotionally I was loathe to return.

Then, of course, there were the issues associated with just getting there. Things fell into place. Doc Elliot facilitated an appointment with one of SK's preeminent gynecological oncologists, wonderful friends loaned us their van (which was a godsend

since we were traveling on the Sunday after my first chemo treatment and I wasn't feeling great), and another wonderful friend helped us find a hotel. Off we went.

As we approached Manhattan, I found myself trying to do what I always did in approaching New York City: orient myself by using the World Trade Centers as a landmark. Of course, this is now impossible and I couldn't tell one end of the island from the other. We decided to drive by the hole where the Towers had stood, because my mind simply refused to accept what my eyes were seeing. Despite having seen the pictures of 9/11, I was completely unprepared for the sight of Ground Zero. From the road, I could now clearly see the building of my former law firm, Cleary, Gottlieb, Steen & Hamilton at One Liberty Plaza. It seemed to stand as a sentinel on the edge of this gaping hole. It was almost as if the buildings had been vaporized, while everything around them was left standing.

Trying to ground myself in some kind of reality, my mind floated back to when I used to wander around in the shadows of the Trade Centers on the way to work. Life seemed so much less angry and complicated. My concerns were with convincing the firm to begin a recycling program, replacing the yellow legal pads with white ones, and writing environmental tidbits in the daily firm newsletter under the pen name, B.Green. (Oh yes and then there was practicing law!) My office had a great view of the Statue of Liberty and, from my perspective more importantly, of ships moored in the east river. We passed the site and my mind went numb. Too many changes had occurred, both personally and in the world as a whole.

Sloan Kettering was nothing at all like I had expected. Instead of a hospital type setting or research-style office, it was a swanky office building. People from all

over the world are treated there, so it was like a mini-UN with a dress code ranging from beautiful saris to suits and the overtone of foreign languages mixed with English (they even took my weight in kilograms!). The waiting room was nothing like my doctor's office. Wherein I enter Doctor Mary's office with a cheery hello and her staff and other patients reach out to comfort one another, in this waiting room, people stuck to themselves.

We waited and I was rather anxious; I hadn't slept much the night before. I was concerned that they might tell me that my doctor was off base, that my treatment protocol needed to be changed, or some other thing that I hadn't yet imagined. I needn't have worried. Upon meeting the doctor, my concerns were immediately allayed. He was great. He confirmed that I was getting excellent care and being given cutting edge drugs. A surgeon himself, he appeared quite impressed by the reports of the surgery and the skill and thoroughness of my surgeon (me too!).

I asked his thoughts on why I may have gotten colon cancer. After all, the common wisdom on how to avoid it is to eat less meat (I've been a veggie for years), exercise regularly (which I have done five to seven times a week for years), and get colonoscopies after 50 years of age (not there yet!). He said that I might be a genetic marker for my family and, if this is the case, it might strike future generations at successively earlier points in their lives. Luckily, there is a great geneticist at Fairfax Hospital and, since the SK pathologists have now confirmed that it is colon cancer, I will pursue this issue in an attempt to safeguard my nieces and nephews or least put our minds to rest that it isn't genetic.

Mom, me and Denise after arriving home from Sloan Kettering. We are wearing hats and shirts from Bob's electrical firm, Pensacola Power & Light.

While ostensibly nothing changed by this trip to SK, in a way everything did. It is critical for me to believe in my doctor and the treatment that I am being given. It was also a relief to have the type of cancer definitively determined. Having these things confirmed gave me a newfound confidence to fight the disease. I have a great team and with that team, the cancer will be overcome.

Physical Aspects I was more prepared for, and ready to fight, the physical impacts during and after the second treatment. Also, Doc Mary true to her word, helped mitigate the vomiting by prescribing tablets made of gold ($100 per pill!). Before injecting the chemo, Nurse Kristen first gives me an anti-nausea drug. Honestly, within seconds, it feels like I've just had a six-pack and out I go. Nausea and queasiness were once more my on-and-off again companions. This time, however, I stubbornly refused to vomit, because I knew that it would mean a return trip to the doctor's office.

There are other related issues that are prevalent with chemo and yet are not talked about in "polite" society but I'm going to, because unfortunately they are an unwelcome part of this treatment and it will help you understand some of the ups and downs a cancer patient endures: they are constipation and what I now call "fire diarrhea". Constipation is a constant concern; even my yoga didn't help during the first treatment. Then "fire diarrhea" finally stormed through my system and it felt like acid excretions which were more painful than anything I'd ever experienced. Lucky me, this experience first happened in a New Jersey rest area on our way to Sloan Kettering in New York. I didn't think I'd ever be able to leave that Jersey bathroom. When I was finally able to rejoin my family, I burst into tears, humbled beyond belief. I will admit that after a few miles on the interstate, we were developing new (and of course marketable) solutions to this problem and convulsing in laughter. Again, Doc Mary attempted to mitigate some of these effects for the second treatment by advising me to take a laxative (bleck) and I increased my intake of raw veggies![7]

There were some new effects this time too. I can't have anything cold to eat or drink for about six to seven days following a treatment, because it feels like ice crystals are forming to close off my throat. Perhaps the more troubling issue is that when my hands and feet get cold, they tingle and I can't feel things. This is a problem for me, especially since I get cold very easily in any case. I have to be careful to guard against this effect, because if it gets too serious it could cause nerve damage and I could be taken off one of the important cancer killing drugs. I am thus diligent about wearing gloves

[7] There are two critical things to ease the "bathroom" issues. First, wet wipes provide a welcome relief; you can even carry the small packages of hemorrhoid wipes in your purse or pocket. Second, and even more importantly, Mom suggested the use of "Bag Balm". This product is one that farmers use on their cows' teats and bicyclists use it for chafing. Yes, I laughed at first and resisted, but it was a godsend. I have seen it at some health food stores and, yes, at farm coops!

(even when it is 70 degrees if need be) and hats. Finally, I am also more susceptible to getting sunburned, not, of course, that we've seen any sun lately in Washington, D.C.!

As you can see, none of these problems are insurmountable and they can be managed. It is also easier now because I know what to expect and, in general, most of the issues go away during the non-chemo week. The fact that I was so incredibly healthy before this disease has helped me immeasurably and it is something that I am thankful for each and every day.

Mind Set Have you ever noticed when you are taking a plane trip that at the beginning of the journey, say in D.C., that certain people look like they belong but as the plane travels to its destination, say Denver, those same people now look out of place? That the Georgetown sweatshirts that seemed so normal in D.C. now look strange among the Patagonias and hiking boots? That's how it feels to be living my life right now: I live in two worlds. Since I am determined to try to continue living my life, on Monday, I went into the office and was happily engaged in my normal routine. As I drove out to my chemo treatment in Fairfax, I felt like I was changing from the "normal" me to the cancer patient. I am simply not yet used to that label or even comfortable with the fact that I am now inevitably and for the rest of my life part of the cancer community.

Although some of you have expressed concern, I had to resume my work. It helps focus my mind in a positive direction and reminds me not to become too self absorbed. It brightens my day immeasurably to open the office door and be greeted by my secretary Alma's wonderful smile, to chat and have my brain tested by my boss Karen's nimble mind, and to interact with my colleagues Pat, Ole, and others. It is, as it has always been, fun. I even held an interagency meeting and, in the midst of the

discussions, would torture my interagency colleagues with some very bad cancer jokes! There is no concern about me overdoing it. I simply can't. I have a certain energy "budget" that I am learning to manage. Also, I don't have to worry about things—Karen and the folks downstairs (the "big bosses"—smile) have been amazing in their support and have repeatedly stressed that my focus should be on getting well and not worrying about work. I couldn't be in a better situation and I so much appreciate the support I've received.

There have been some rather unfortunate events that have tested my mental state. For instance, while most of you share stories of tremendous courage and survivorship of people with cancer, one person told me of the three people she knew who had died from cancer. Then there was the unfortunate incident in a conflict management seminar attended by my NOAA colleagues where the speaker, in trying to make an analogy, stated that Stage IV cancer was a sure death sentence. Funny enough neither of these incidents really bothered me, because they don't apply to me. What has bothered me and reduced me to tears these past two weeks is dealing with the uncertainty of whether my 17 year old nephew's brain tumor is cancer and finding out that my dear friend, who I met when we both clerked for Judge Keep in San Diego, has Stage III breast cancer (Judge Keep died from ovarian cancer in September). I worry more about them and my other friends with cancer than myself. My illness is just a fact of my life and I will get through it.

I am struggling to adapt to my two worlds and adjust to the new rhythms of my life. I am also coming to grips with the fact that cancer most certainly reduces life to its basics: eating, sleeping, and bathroom issues. I've stopped asking "why"—it only

matters if it is genetics and otherwise, worrying about it and asking this question is simply a useless outflow of energy.

I'll leave you with my favorite thought for the week, which was given to me by my wonderful brother. He told me that it isn't what life hands you or what you have in life that is important, it is the attitude with which you deal with these circumstances that is critical. I choose to maintain a positive attitude through this and so much appreciate the support you all have given me in doing so.

Thanks for listening,

Lindy

Too Toxic

"Illness is the most heeded of doctors. To goodness and wisdom, we make only promises; pain we obey."
Marcel Proust

Hi there—It's me again. These past two weeks have been rough. At one point I actually wondered if the remedy was worse than the disease. My logical mind stomped out this irrational, cowardly thought as soon as it formed. After all, these effects will be but a distant memory and the drugs will ensure the celebration of my health for many years to come.

Everything just seemed askew and more poignant. The treatments were on Tuesday and Thursday instead of Monday and Wednesday, because of the Memorial Day holiday and, although this seems minor, it threw me off my stride. Additionally, based on the advice of the drug company, they accelerated the speed at which they gave me the Wednesday drug (the same amount in one-third the time) and my body reacted badly.

I had to be given two anti-nausea drugs to counter the effects. As the week of the treatment ended, storm clouds gathered both literally and, for me, physically. With excitement and anticipation as the wind picked up and thunder rumbled, we sat on my deck watching black clouds gather and lightning brighten the sky. I began to feel worse, almost as if my body was responding to the changing atmospheric pressure. My storm broke first. For almost five hours, I battled "fire diarrhea" as the chemicals raged through and left my system. I was left exhausted and spent after each bout. Trina-pie, my

Montana sister with her unswerving upbeat attitude, alternatively cradled me or made me laugh as tears streamed down my face. Just before midnight, the rain started to fall and I felt a release. I just knew that the worst was over and that the chemicals were gone—there was a feeling of lightness and clarity throughout my body. Prompted by an email from a dear friend, I fell asleep doing visualizations of the rain, which was now falling loudly and steadily, washing away the cancer and the ill effects of the medicine. At peace, I finally fell asleep.

Nesa, me, and Trina-pie during a lighter moment.

I called my doctor the next morning. While I waited a few minutes on the phone, Nurse Jen spoke to Doc Mary who indicated that my chemo dose would be adjusted so that we could avoid this effect. I resisted at first, because if it was a choice between killing the "bastard seedling" cancer cells (as Trin so appropriately named them) and

having even some of them survive, then I would endure the fire diarrhea! She overruled this idea, because if my system becomes too toxic, as was evidenced this week, then they may have to stop the treatments altogether while I recover. By lessening the dosage, they hope to avoid this outcome.

I had several conversations with Doc Mary and her staff this week, as well as another doctor, and I slowly realized how hard they are hitting me with chemo. Although one of my friends with breast cancer has treatments once every three weeks, I really don't have any baseline to tell what is "normal" and what is getting hit hard. Each person gets their own brew of chemicals, which is probably based on weight, age, and type and stage of the cancer. Lucky me, since I have Stage IV, they need to hit me hard. I guess this is why they preach about early detection with colonoscopies, eating less meat (including my "clients," seafood), and exercising regularly. (Yes, I know none of these things made any difference in my case, but it is always better to reduce the risk, isn't it?)

The Difference a Doctor Makes My family is, unfortunately, learning much about the medical profession and differences in care. On the one hand, we have my nephew's experience. He had a brain tumor removed in November, but they didn't get it all and it has started growing again. Unfortunately, it seems that the doctors gave him an injection of steroids before surgery which apparently compromises the ability to determine what the tumor is. Notwithstanding, a number of tests have been done on the tissue by some well-established institutions and they have come up empty-handed. When his Florida doctor threw up his hands, he was sent to the Children's Hospital in Birmingham, Alabama. More tests, more inconclusive results. Then, the unwanted news: they have to go back into his head and there is a good chance that it may

be brain cancer. Heart wrenching, terrifying, denial—he's only 17. After gamely celebrating graduation, Zack started having terrible headaches and throwing up. We held our breath and worried, until they discovered the problem was that the pharmacist had given him the wrong dosage of seizure medication. Sigh.

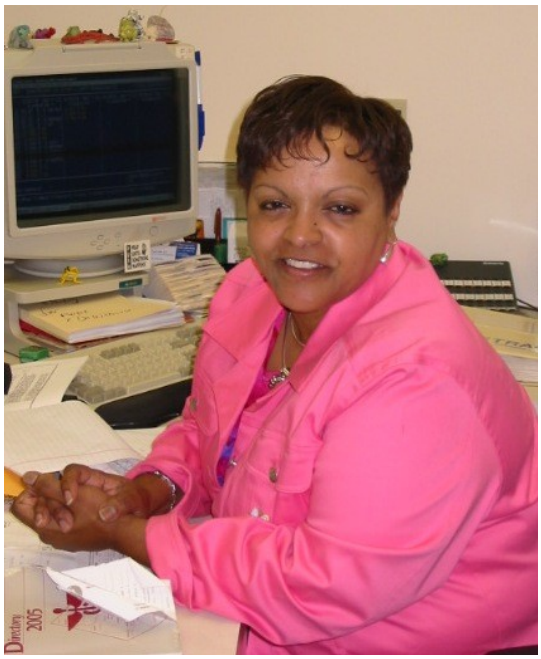
My brother wants more answers from the Birmingham doctor before they agree to another surgery; he has held one-way conversations with answering machines, conversations with nurses not doctors, and was given varying information on key questions. Zack adamantly doesn't want to undergo another procedure and, under Alabama law since he is over 14, he has to sign off on it. My brother is thus trying to find a way to get a second opinion to show his son that he's doing everything possible before committing to another surgery. This has resulted in problems with insurance coverage, an inability to get an appointment in a timely manner, more answering machines, and more waiting. While the clock ticks, each day has been filled with worry and fear, as Bob vainly tries to find a doctor to whom he can fully entrust the care of his son. The rest of us just sit helplessly by, listening as the saga unfolds and pacing the floor. I call my brother "Sunshine," because he gives me and others such warmth and love, and yet all I can do is sit by the phone and pray that the black clouds in his life soon dissipate.

My Sunshine

My care, on the other hand, has been fantastic. I know from the second opinion from Sloan Kettering (thanks to Dr. Elliot for breaking down the doors to get me a timely appointment) that I am getting excellent care, that my treatments are the best I could be getting, and, perhaps most importantly, that the diagnosis is correct. This certainty provides me with a solid basis for confidence and trust in my doctor and leaves me free from worry to concentrate on getting better.

I call my caregivers "Team Smiley," which just happens to be the last name of my primary nurse (Kristen Smiley) and yet it epitomizes everyone in the office from the receptionists, to the nurses, to the doctor. They go out of their way to put people at ease and make them feel as comfortable as possible. On the very first day, as my parents and I were waiting nervously in a room for Doc Mary, Sandy—the glue and penultimate organizer of the office—saw us sitting there and just stopped by to say hello and chat. It helped immeasurably to ease our tension. Led by Doc Mary, Sandy, Kristen, Jen, Kathy,

Maria, Lindsey, Triscilla, and everyone in that office create a culture and atmosphere that make a difficult experience easier. I love it that, although unfailingly professional in their care, I am greeted by smiles and even hugs when I arrive.



Sandy, the organizer and "live wire" at the office!

I am given topnotch care 24/7. During my treatments, I have made it clear that I always want to have Nurse Kristen, because she is familiar with how I react during injections, the order which I should be given the drugs, and my general health history. I have also been instructed to call whenever I have a question or there is any issue with my health. And this is the part that simply amazes me, I reach a person no matter what time I call—of course, I tested this at 9:00 p.m. on a Sunday! The receptionist offered to get me a doctor within two minutes to respond to my question.

A fact that probably won't come as a surprise to any of you who know me, I have one book where I keep track of everything—all my questions, how I feel, and anything related to this cancer journey. The nurses and Doc Mary have now become familiar with the pink book and wait for it to come out with my typical barrage of questions. When I

ask my questions of Kristen, she immediately checks with Doc Mary, who wants to know —and express an opinion on—everything. As I said, she's a control freak and I love it. Her belief and objective is that I should be living as close to my normal life as I can and, apart from hiking Kilimanjaro in August and going to China for work, she doesn't try to hold me back.[8]

Everything is carefully monitored. The same procedure takes place each time I arrive: akin to a weekly Weight Watchers meeting, I get weighed in and they take my blood pressure and temperature. I have periodic meetings with Doctor Mary and blood tests every other week. Once every three to four weeks, they test for the cancer indicators. I got my first results back this week and my numbers were in the normal range, meaning that I really don't have cancer! I was hopping around the office, saying loud goodbyes to all the staff, and didn't notice that my quiet mannered doctor had come up behind me with another patient trailing her. She drew my euphoric balloons a little bit closer to the earth, as she told me that no, the numbers did not mean that I would not be seeing them anymore, but that the treatments were working. Although that news did sober me up a bit, I left the office with a spring to my step. It was the first good news that my family had received in a long time and we celebrated.

Looks, Effects, Perceptions and Reality I was standing on the elevator the other day at work and there were three of us: a man holding a container of donuts from the cafeteria with his belly spilling over his belt, an overweight woman who was breathing laboriously, and me. I smiled to myself. If anyone saw the three of us, they would have probably picked me as being the healthiest person on that elevator! It was yet another

[8] I have tried to capture in Appendix 1 those elements of Doc Mary's practice that—from my perspective as a patient—make it a wonderful place to be treated. I call these elements, "Doctor Mary's Methodology".

lesson in not judging people by their outside packaging and cutting people a break because we cannot know what is going on in their lives. For those of you who have not seen me in person, I look exactly the same as usual. My hair is hanging tough, I'm not at all gaunt (in fact, I'll probably be the only person in the world to gain weight while on chemo!), and, when I get enough sleep, there is still an enthusiasm for life and a smile on my face. I just don't look like I have cancer and, every other week, I am still maintaining that I don't and that I am incredibly healthy. I will admit, however, that I have been a bit slower this week and could feel the effects of this dosage a lot more.

One thing that helps me through the treatment weeks is building wonderful memories. For instance, I had a great Memorial Day weekend. I created memories that have held me through these past two weeks: I went out kayaking to see the birds and just be outside and, thanks to a very dear friend, I got to see my beloved Tigers trash the Orioles (sorry Baltimore fans, it was a great game). I feel great during the daytime, but I find that I must remain quiet in the evenings to regenerate for the next day.

The side effects continue and have been habit forming. When reaching into the refrigerator, I use a towel or gloves to avoid the tingles in my hands. Cold drinks and food are out for seven to ten days and I find that by the time I remember that I can drink them again, it's time for another treatment. Since the chemo is killing the rapidly dividing new cancer cells, it apparently shocks my bone marrow from producing any cells for a few days. This has an effect on my immune system, so I am wary of people with colds and avoid going needlessly to places where I might pick up something (*e.g.*, public transportation). I'm just happy that I picked the right time of year to have cancer, since it is summer and there are few people with colds! Another funny side effect is that

my voice during chemo weeks gets rough. I laughingly call it my sexy voice, although I find it rather annoying and it takes more effort to talk (don't worry, it doesn't slow me down). Queasiness is a constant companion, as are "bathroom" worries. And finally, I cannot deny that I have a lower energy budget. I have never liked to admit to being tired and generally I have boundless energy. Now, I have to be careful, because if I get too tired I can't sleep and get a pounding headache.

None of these things are insurmountable; they just have to be managed. In fact, my dear friend from babyhood (who has three kids) and I have discovered that there are a lot of similarities between having cancer and being pregnant. Seriously, don't laugh! There are the weird food cravings, feeling queasy, and the "bathroom" issues. Also, there is definitely the similarity of the energy budget. Becoming too tired can result in being overwrought and tears flow more easily than normal. Then there is just the general feeling of being out of place in your own body and space, and being helpless in understanding its reactions to what is growing and happening inside. On a positive note, both the chemo treatments and being pregnant are life affirming. At the end of both, there are so many reasons to rejoice. Now that I think about it, there may in fact be some benefits to having cancer rather than being pregnant: my treatments only last six not nine months and I will be able to sleep fitfully throughout the night afterwards! Seriously, as I've said before, since my cancer journey started on my birthday, I strongly feel it is a gift of life. While Sarah and I have laughed over these similarities, it has left me with the more serious gift of being more compassionate and understanding of pregnant women!

Sarah, Nicole, me and Matthew

Reactions and Actions There is a definite reaction from people when I tell them I have cancer. The reaction is instant compassion and worry; some people actually look horrified. I hurriedly tell this latter group not to worry that I'm not contagious. It seems that there is a perception, perhaps rightly so in some cases and in the past, that a person with cancer is on her way to her deathbed. I hope to change that perception, because—although I too will die someday and may be even from cancer—I am still very much alive and kicking.

So, I talk about it, casually and to strangers. I want people to understand that a person with cancer can live an absolutely full and normal life; of course, a person is comprised when undergoing chemo, but so is a person who is recovering from back surgery or a broken leg. I don't know, maybe I'm making too light of it and I'll be writing to you in seven months to recant. But I don't think so—I've talked to several wonderful people who are cancer survivors and, unless they had told me, I too would have been worried that having cancer meant a sure death sentence. I'm taking this

attitude not because I don't think this disease is serious, I have it and I'm serious about beating it.

I guess the concern for me is, especially since I've been so public about this illness, is how people will treat me after I finish the chemo. Will there be a feeling that I'm somehow different and less able to do things than before? Well, I admit this disease has already changed me—that much is evidenced by me making my private life public! The changes that I've noticed, however, have been gifts of change for the best, of growth, attitude adjustments, and reflections of possibilities.

One of my dearest friends once mused to me that if you have a dreadful disease that makes you look death in the face, it should change the way you live your life. You would hope not to spend any time being petty or getting upset about silly things, and it should encourage you to spend each day as if it were precious. Well, I had (and have) such high hopes for myself and I repeat some of the lessons I've been learning silently to myself each day so that I won't forget them. And yet, there have been moments when my Aries temper has gotten the best of me and my old habits resurface. After the moment has passed, I'm left shaking my head. It's all well and good to have good intentions when life is calm, but the trick is to maintain your calm when life is not. So, I vow to myself to try again, count to 10 (or 100) even when I don't feel like it, and keep trying to instill the lessons I've learned from cancer into my day to day habits. Unfortunately, I still have a long way to go!

Connections As I said, the past two weeks have been rough. I have been terrible about returning phone calls, writing my thank you notes, and reaching out to all of you wonderful people that have offered me assistance and support. I have called many of you

and written to you as I have been falling off to sleep; unfortunately, it's impossible to put postage on my thoughts! To those that have so generously offered food or other support, I just don't know what to say. I still don't know how to deal with the food issues and, especially during chemo weeks, I don't know what I'll feel like eating. And, since I don't have cancer every other week, I almost feel like a fake asking for help. Like I said, I just don't know what to say, except that I hope you won't take it that I don't truly appreciate the offers of support, the phone calls just telling me you're there, the emails, and always the funny cards. I am trying as much as I can to live a normal life, but believe me, there are parts of it that are anything but normal.

I have to have cancer again tomorrow and it's off to "druggieland". Be well yourselves, live life large and always always laugh a lot. Thanks again for listening,

Lindy

PS By the way, before I sign off, it has occurred to me that these emails have grown "legs". I am truly touched and honored if you feel you want to share it with others, be my guest.

The Unavoidable Question

"I recommend almost dying to everybody. It's character building.
You get a much clearer perspective of what's important and what isn't,
the preciousness and beauty of life."

Astronomer Carl Sagan

Hi there—Fair Warning: This email is lengthy and deals with an issue that you probably do not want to think about—death. Therefore, please, avoid it if you feel to do so would be better for your health!

Time marches on, I'm already one-third of the way through my chemo treatments. I am elated! One of you mentioned that you thought that time must be going by fast since there is such a demarcation between the weeks of my life. Unfortunately, this could not be farther from the truth. On the contrary, it feels as if Father Time has lead in his boots. There are times when each day—and sometimes each hour—is excruciatingly long. I wryly smile during my good moments, remembering my wishful thinking before I had cancer that time would slow down! During the non-cancer weeks, time marches away from me much as it did before this journey began and then, treatment week descends and each day is carefully marked off and its closure celebrated as another small victory.

Peering Over the Edge So, what if I do die from this disease today, tomorrow, or even next week? Anyone who has cancer has undoubtedly faced squarely the question of his or her own mortality and I am no different. We all know that life and death are the natural progression of life and yet, death is something that most of us prefer to think

about “later” or that we’ll deal with it when we get old. Some of us may begin to think about the issue when a loved one dies, but more often than not our mind quickly darts away from the topic and thankfully goes back to the details of living. If we are relatively young and healthy, we justify our postponement since there is really no pressing reason to think about such a morbid topic. Those of us in the cancer community do not have that luxury.

It took me some time before I could admit to myself that I had cancer. When my gynecologist told me that I had to go see an “oncologist” (a word I’d never bothered to define), I blithely believed that I could go by myself. Thankfully, my sister Nesa knew better and flew in on a day’s notice. As my surgeon methodically went through all the reasons that he knew I had cancer (*i.e*., 8+ pounds of fluid in my right lung, complex tumors, and elevated CA125 cells), my mind shut down and I stopped taking notes. I began to focus only on the fact that I had to have surgery; I couldn’t bring myself to think about having cancer and what that might mean. I simply sat there as he scheduled the surgery, the post op, and even talked about chemotherapy. While I heard and understood the words, my brain simply refused to accept that reality.

I faded into unconsciousness before surgery (laughing hard, as usual, at something Mom had done) and awoke the next day. As my eyes came into focus, I saw on the wall a poster with the words “CANCER” written across the top of it. Since I had other things to keep my mind occupied, I ignored it. My surgeon came in to tell me that I was scheduled for another minor surgery to install a medi-port to facilitate chemotherapy injections. There it was again, cancer just kept creeping into my life. Too uncomfortable with the tube in my nose and down my throat to think about it, I just

nodded. The people who installed the port were a lively crew; they didn't mention anything about the "c" word and their joking around masked the seriousness of their job. Although it was a simple process and I was soon back in my room, they literally left in me an indelible mark. Even today, it is the port that destroys my ability to pretend that I'm living my life as normal or that, even for a few moments, this is just a nightmare from which I can awake, cancer-free.

The "cancer" word just seemed to be in the air at the hospital. My surgeon would refer to it on his morning visits. And then there was that sign. It just hung in my psyche: I had to pass it on the way to the bathroom or on the way out the door for a short walk, it was there every time I was awaken by the groaning or belching of my roommate-behind-the-curtain, and it was hung just high enough so that I could see it over the smiling faces of Mom and Nesa when they refreshingly bounced into the room each morning. As it stared at me, I decided that it must be in every room in the hospital. My mind refused to even consider that perhaps I was in a "cancer ward" or the cancer wing of the hospital; I didn't even bother to ask. I did, however, work hard to get out of there.

On the day of my escape, a woman came in to see me. She literally exuded an air of gentleness and compassion, combined with a rather businesslike attitude. It was time to get on with life. She was from the hospital's Life With Cancer Department and was there to tell me about the vast array of services available to those of us with cancer. I must admit, my protective armor went up immediately. I did not yet accept that I had cancer so I didn't need to talk to her. Undoubtedly she'd heard it before: "I'll call you later." She nodded and left me some information and her business card. I didn't even bother to look at it. Mom and Nesa simply packed it up and brought it home.

At home, I was free. No one raised the issue of the dreaded disease every morning, there was no sign, and I was left to concentrate on healing. Unlike the cancer which I hadn't felt at all, I could feel and deal with the effects of surgery. That being the case, why should I accept that I had cancer? My subconscious, however, was busy ensuring that I would eventually come to grips with my new reality. One night, I had a dream where I told a friend that I had cancer. There was no emotion, it was just a statement of fact…and then we went off to a street fair complete with beautiful vegetables, flowers, and dancing clowns (yes, the usual nonsequitur sequence of my dreams). The next day I began to make cancer jokes. There was no hesitation on the part of my family; they laughed, joined me in making jokes, and helped me to accept and deal with it as a fact of my—no, our lives. With that, the elephant in the room sighed in relief and departed.

So, now that I accepted that I had cancer, I had to deal with an entire range of emotions. The thought of cancer is always accompanied by fear and horror, with the issue of death lurking assuredly nearby. While I knew people who had had cancer and are still living wonderful lives, I had the most advanced stage of it. A dear friend and my sister Trina-pie did some research for me on the drugs and on colon cancer. After reading a bit, I decided not to read anymore. I simply did not and do not want to know everything about the possible side effects of the drugs or the statistics of those with Stage IV colon cancer. After all, I was going to deal with whatever happened and, as for the statistics, some of them were dated and collected before they started using some of the drugs that I'm on now. Most importantly, these statistics do not include my body or my spirit.

Then there was the issue of death. There were several nights that I awoke, wondering what my future held or whether I was even going to have a future. My meditation room was a godsend during this time. It is a place where I have tried to train my mind to come to rest and be at peace, even when it felt like trying to herd cats. If fate led me to this practice only to deal with those nights, I am so grateful. It helped me to be at peace, go back to sleep, and get up the next day with a smile on my face.

So, what if I do die? I have had such a great time in my life; I have a wonderful family and an eclectic and loving family of friends. I've traveled to some great places, participated in great adventures, and tried to make a difference in the world through my work. If I were to die, I decided that it would be okay.

I carted this decision around with me for a few days. It seemed to get heavier and heavier as my family cheerfully shouldered and supported my healing process while also working hard to turn my backyard into a green paradise. There was also the support from other family members and friends that just kept pouring in, reminding me of life and laughter. My decision that it was okay to die began to feel like a cop out, like someone had "fixed" the fight against the disease so that I would lose. Therefore, given all the unconditional love flowing my way, I simply couldn't sustain my decision. Moreover, I'm not a quitter (as some of you know only too well…) and that's what it felt like. So I started to focus on all the things I want to do. I want to go to Tibet, Egypt, and Antarctica (at the very least); follow through on our hike up Kilimanjaro (we'd finished the planning for our August trip two days before my diagnosis); spend a lot more time learning about and teaching yoga; rejoice, laugh, and talk with my family and friends; and then, of

course, there is that Right Whale Ship Strike Reduction Strategy that remains to be implemented.

Although the attitude you take toward whether you want to live or die can make a difference, it really isn't up to us to decide whether we've done a good enough job in this life so that we can die or that we have things we want to do so we aren't going to die yet. I had always lived my life with the touchstone of, if I can make even one person's life better during the day, then I have earned another day. While my cancer diagnosis seems to mock this code of conduct, I cannot—because of habit, the way I was raised, and my attitude toward other people—jettison this approach to life. And yet, I still had to deal with the unavoidable question: what about death? Being me, I decided to deal with it logically and systematically. First, I panicked. Nesa, as my executor, was going to be very upset with me since my paperwork is not in order, my house needs to be de-stuffisized, and there may even be science experiments in my fridge! After calming down a bit, I decided that I'd have to deal with all of these issues—except the fridge which was dealt with immediately—more methodically over the next year.

I then let Nesa know that, in the unlikely event that I do die, I want one poem ("Success" by Ralph Waldo Emerson) and two short passages, one by Edward Abbey and one by Paulo Coelho, shared with my family and friends.[9] I also long ago decided that I did not want a tombstone to bear my name or to leave any other mark on the earth. My ashes could be spread in part over the Tetons and in part over the ocean (after getting an ocean dumping permit, of course). I do not want any funeral or other teary memorial: I want only parties where my family and friends celebrate each other and life in general—perhaps a kayaking party complete with my friends the beavers, herons, and osprey; one,

[9] They are reprinted in Appendix 2.

of course, at 8841 Bergin Road with all the extended family on both sides; one in the Tetons wherever a moose can be found; one at Nan's farm where we've spent so many wonderful times; and one out at Assateague at sunrise in the fall, when the wide expanse of the beach is filled only with the sound of crashing waves and madly darting seabirds. It actually doesn't really matter where the party or parties are, only that people have a reason to get together to have fun, swap stories, and build memories.

Then there was the difficult question of what happens when my spirit leaves my body. Ooooh, now this is an intensely personal question and one that can vary so widely for each of us. I was raised Catholic and yes, I actually played the organ for our church services from sixth grade until I graduated from high school (my favorite was playing a lot of bass to "Oh When the Saints" or "Oh What a Beautiful Morning" as the congregation left the church). If I followed my upbringing, then I would believe that there is a heaven and a hell. I must admit, I sometimes like to think that there is a heaven because that would mean that my grandparents are definitely there. Grandpa Johnson would be singing in the choir, Grandma Johnson would be watching over me to make sure that people were treating me fairly, Grandpa Foldenauer would be beating people (loudly) at euchre, and Gram Foldenauer would be giving Gramp the business. In those moments in life when heaven really needs to exist, I talk to them—and, even if it doesn't, it makes me feel better. As for hell, well, I just don't believe in it.

Over the years, I've become increasingly drawn to the philosophies of eastern spiritual practices. It probably started from reading too much Nietzsche and other political philosophers in college or because a friend joined a cult that the Catholic Church mistakenly and temporarily supported. I began to have too many questions about what

people do in the name of organized religions, in particular when they are used for political purposes such as the conservative coalition or even radical Islam or radical anything. One of my primary touchstones is, however, taken from my upbringing. I call it The Golden Rule Lite: "Do Well Unto Others". In my personal philosophy, I remove the last part of the rule, because I don't like it. The "As You Would Have Done Unto You" seems to introduce a quid pro quo—or if you don't, I won't—element into relationships. That is, the only reason that you would do good things is because you want good things to be done for you or, alternatively, you are afraid of people doing you in! I simply don't want to live life based on fear or have a Machiavellian approach to life. It also seems to be a very self-centered approach and there just has to be something greater than individuals.

So, at the risk of alienating some of you, I guess I'll come clean regarding what I believe and how it has helped me cope with the issue of death. I truly believe that every single living thing on earth is due my respect—okay, okay, even though I have a general catch and release program in my house, I have trouble with the mosquitoes and ubiquitous flying moths! I wish them well as I squish. After a great deal of thinking about it, I also believe in reincarnation and the continual evolution of my soul. This is why I believe so strongly that this cancer journey that I'm on, coming as it did on my birthday, is a gift meant to help my soul evolve. I also know, because of this belief in reincarnation, that my soul is not ready to depart this world yet; I have a lot more to learn here before moving onward.

I believe in a higher power, which I happen to call God, because quite frankly I failed to come up with another word to call it (even though for several years I tried very

hard—I wanted to avoid the baggage of whether God was a "He" or a "She" or some of the other issues that seem to separate people in the name of religion). Am I right? Who knows? I must admit, in a way, I envy the dead. They, after all, know the answer to this age-old question of what happens in the afterlife.

After looking death in the face, I'm convinced that it really doesn't matter what I think—or anyone else thinks—about death. What does matter is how we treat each other here and now, and I'm grateful because cancer has taught me some valuable lessons in this regard. It was also important for me to define the touchstones that guide my life. I am not the type of person that can just let each day meld into the next, without having some kind of overall meaning and organization to it. I'm content now. If I die today or tomorrow, I am okay with it. This thought, however, is different than when I initially had it. This thought is now empowered by my opinion of the meaning of my life and, armed with this, I actively engage cancer in battle; I am learning the lessons it has to teach, taking the good with the bad, and, if nothing else, maintaining a good attitude because this is only a temporary condition of this life.

Side Effects Doc Mary decided against reducing the dosage of my drugs (or I had been hopeful that the dosage would be reduced and thus had misunderstood her), as I had thought when I wrote my last email. She wants to maintain it as long as I can stand it and kill these bastard seedlings. Although at first I groaned, I had to adjust my attitude and deal with my fear of the side effects. If she is going to fight hard for me, I have to too. I braced for the side effects and my family and friends came in to support me. Dad came to see me through this treatment cycle (what a wonderful Fathers' Day present!) and, when he left, Karen came to help me face off against the inevitable and expected

onslaught of the side effects. My worst fears were thankfully never realized and I literally danced a jig. No "fire diarrhea" this time! During the chemo week, the nausea was worse than it has ever been and I found myself sleeping a lot more. The other effects of not drinking cold things, tingling fingers, interrupted sleep, and "bathroom issues" (without the "fire diarrhea") remained the same. Although I could be wrong, it seems that the truly bad stuff happens only every other treatment. If that's the case, that would mean that I only have four more really bad times—and hey, that's not bad at all, I can live with that!!

I've been told that the effects of the treatments are cumulative, which means that supposedly the effects will be getting worse. I will admit that even during the non-cancer weeks, I sometimes get an overwhelming feeling of being sick. Dad told me to just think of these times as the dieing off of cancer cells and Mom has always advised me when I was feeling uncomfortable to concentrate on other things. Armed with these pieces of advice, I simply muster through these times and the feeling soon fades.

Conclusion My apologies for such a long email. For those of you still reading, thanks for bearing with me. I had to address this part of the journey. No doubt it will come up again and again in my (and your) life and my thinking may change. From my perspective and my personality, I needed to deal with it head on and come to a peaceful resolution. In achieving that peace, I'm free to concentrate on the battle at hand and enjoy life. This past week I have definitely done that.

Thanks to a dear friend and my nephew, I've been out in my boat twice—to Pohick Bay, my favorite paddling place, and to a brand new place on the Potomac, complete with rapids and "riffles". I have also begun to swim again slowly, but

regularly. I have also discovered that my goalposts in life have moved. The important thing isn't how fast, how far, or how much I can do in the day, but simply to live my life fully and enjoy it, right down to its mundane banalities. Life is a very wonderful thing!

Thank you for sharing my life with me and thanks for listening.

Lindy

My view of heaven on earth!

East-West Integration

Peace for the body, Peace for the mind. Peace for the Soul.
Om Shanti, Shanti, Shanti. Om Peace, Peace, Peace.
Sivananda Yoga Tradition

Happy 4th of July! I'm celebrating—no, not because of the holiday, but because it's been a banner week for the Johnson family. I received the results of my monthly blood tests and the chemo is working. My nephew had surgery on Wednesday to obtain tissue for a biopsy. Unlike the last surgery, he came out of it feisty, talking, and fully functional. He was discharged the next day from the Intensive Care Unit, where the nurses and doctors had to learn for the first time how to discharge a patient. The biopsy results should be available this week so that plans can be made to ensure his complete recovery. While we are once again in a difficult waiting mode, at least the path ahead is much more clear. Life and modern medicine are truly things to celebrate!

"Take two pills and call me in the morning…" Throughout my life and in particular over the last five years, I have done my best to stay away from western medicine. I chose instead to adopt alternative healing techniques wherever and whenever possible. Staying healthy through diet, exercise, mental attitude, and acupuncture was a conscious choice and even, in most cases, a consummate passion. This choice, however, came only as a result of living through surgery in 1998 to remove fibroids. When my gynecologist told me that I'd probably have to face surgery again, I was determined to do everything I could either to avoid it altogether or to postpone it for as long as possible. This decision led me to my wonderful acupuncturist who in turn opened my world to

eastern philosophies and meditation, things in which I'd always been interested but didn't have a clue how to pursue. In short, this decision changed my life and expanded my view of the world. I strongly believe that eastern healing techniques support western medicine and vice versa. My cancer journey has only served to underscore this belief.

Yoga and Flexibility Many people believe that the practice of yoga is simply a physical exercise aimed at maintaining flexibility. For me, it goes well beyond that to encompass a lifestyle, a mindset, a stress relief, and an insurance policy for a general sense of well-being. My yoga mat is my constant companion; I have one in my truck, one upstairs and one downstairs, and one for traveling. The mat in and of itself is not absolutely necessary for the asana postures, but it is critical because it defines a space literally and figuratively where the mind can be coaxed into concentrating on what is happening in that space instead of chasing after every wayward thought that arises. In addition to the mental benefits, yoga has helped me listen and pay attention to my body. Little did I know that someday it would play a role in saving my life.

In February, when I was doing the "cobra pose"—which involves laying on your stomach and pressing up on your hands (thus pushing your abdomen into the floor)—I began to feel a small bulge on the left side of my lower belly. My gynecologist had told me seven months earlier that some fibroids had begun to grow again and, although a bit concerned, I attributed the bulge to that. Since my schedule was incredibly busy until April, I decided to wait before going to see my gynecologist. I could tell, however, from my daily yoga practice, that the bulge was growing incrementally. With my excellent health and because "Dr. Johnson" had diagnosed the bulge as a fibroid, the fact that it could be something life threatening never crossed my mind.

When we ignore signals, the universe—and our bodies—have a way of getting our attention. I had to be hit over the head before I got the message. First, I had mentioned my "fibroids" to my family and they urged me to see my doctor. It was only after seeing my acupuncturist, however, that I acted. In fact, it was her persistence that did it. She suggested during my treatment that I see my doctor; however, I got busy the next day and didn't get around to it. She surprised me when she called to make sure that I had followed through and insisted that I tell my doctor that it was an "emergency." That word got my attention and I made the appointment.

The second signal came from my body. I thought I had a chest cold. Of course, the most annoying thing to me was that I couldn't swim. So again, at the urging of my acupuncturist and friends and family, I decided to get some antibiotics from a "doc in the box" (walk in clinic). I located a clinic late in the evening and, since I had signed up for a yoga backbends class in the morning, I decided to go after class. During the class, we did a number of postures including headstands, handstands, and a variety of other back bending poses. I knew at the end of class that the chest cold had settled in my right lung. Was I ever surprised when the X-rays taken at the clinic revealed that about 90% of my right lung was filled with fluid. The doctor was amazed that I was still walking around and, incredibly, that the tests showed that I was still able to breathe 98% oxygen (she did the test and was only at 94%).

The walk-in clinic doctor sent me straight to Alexandria Hospital's emergency room, where they removed over four pounds of fluid. It was there that I first heard the word "cancer." Since I didn't have any visible signs of an infection or other illness, the

lung doc said that they would check for a variety of things, including cancer.[10] I, of course, dismissed this possibility; after all, I was in great health! It was only the next day when I visited my gynecologist that this word became part of my reality. They removed a further 4+ pounds of fluid before surgery and, luckily, the fluid showed no signs of cancer (of course, we were told that these tests are only 50-60% accurate—I decided to ignore this statistic). The fluid in my lung was one of the worst parts of this journey. It felt like I was drowning from the inside out.

So, if I ever had any pride in the fact that I practice yoga and like to think I listen to my body, this experience taught me humility and at least one very important lesson. It isn't enough simply to listen to my body and note certain things (*e.g.*, a bulge!), it is critical to act on the signals that it is giving me!

I have started my yoga practice again. After surgery and before chemo, my Mom strongly encouraged me to keep up with those things that are important in my life, such as meditation and—to the extent that I could—my yoga. She thus gave me the space each morning to go to my meditation room and face myself. The demons were waiting for me behind the door. After going through surgery and being told that I had a life threatening illness, there was a fear and barrier that had never been there. The yoga practice that had flowed so easily and effortlessly had turned into a practice where it felt like I was moving my limbs through peanut butter.

I can't articulate the fear that was balled up inside me as I faced my mat. And yet I had to stay to face it. After two to three days, I attempted the headstand. It is called the king of asanas and one that I had worked hard to accomplish. I felt that if I could do a

[10] I don't quite understand the medical reason for it, but my many tumors apparently caused a build up of fluid and it seeped through my diaphragm into the lining around my lung.

headstand, I could continue with my practice. I didn't stay up very long, but I did it. I ran downstairs and did another one for Mom and—to my surprise—immediately broke into tears. I had crossed a watershed.

I won't pretend that my practice today is anywhere near where it was before surgery. After all, before surgery, I had been practicing daily for a long time. To my immense gratitude and as a sign of their synchronicity, my Dad recently echoed the advice that Mom had given me. He advised me to carve out a specific time each day for my yoga practice or to swim and, because it was essential for me to heal, that I should not let anything detain me from doing it. I took another important step during my last treatment. My dear friend Monique came in from Montreal to stay with me; we had gone through "Yoga Boot Camp" together to become yoga teachers. Notwithstanding the fact that it was a treatment week or that I had the chemo box attached to me, we did our practice. Each afternoon, we did an amazing yoga relaxation called Yoga Nidra.[11]

While some may view this as a failing, I will admit to being a creature of habit. Now that I have started my practice again, even during the treatment weeks, I will try to continue it unless my schedule gets completely disrupted. With each day and to my immense relief, both my body and mind are becoming stronger and I am regaining flexibility.

[11] For any of you who are under stress, I highly recommend buying a CD with Yoga Nidra on it. Everyone can and should experience and benefit from this relaxation technique.

Me, doing a yoga pose while camping in the Tetons, with a moose in the background!

Before leaving this subject, there are two other yoga techniques that have helped me immeasurably. I went from being someone who tried to avoid taking medicines to being faced with having hazardous substances injected into my body. I was searching for how to think about the drugs in a way that wasn't negative; after all, this stuff is supposed to heal me! Not knowing any other way to handle it, one morning, I simply let it go in meditation. Call it coincidence or a gift from the universe, but the next morning and a few days before my first treatment, I received in the mail a CD from a dear friend with exactly what I needed. It was a relaxation technique for use during treatment in which you welcome the medicine into your body as you inhale and expel the cancer as you exhale. I listened to this CD until it became ingrained into my thought process. Now, I don't resent the drugs or being hooked up to the box. Instead, I greet them as life giving, and try to envision the drugs as a necessary healing tonic spreading throughout my body.

For those of you who don't practice yoga, the last yoga technique that has helped is what I'll refer to as the rock & roll technique. Do you know how some music

makes you tap your foot or puts you in good mood? Just imagine driving down a beautiful, curvy country road on the first bright, sunny day of spring and your favorite rock and roll song comes on the radio. Doesn't it make you feel great (especially if there are no cops around to catch you speeding)? My wonderful yoga mentor from the Sun&Moon Yoga Studio came over last week to teach Monique and me a "mantra," the yoga equivalent of that rock & roll song. It speaks to the soul and is said to have healing vibrations. I also have several other CDs, given to me by some of you, that speak to my soul. They have provided a welcome relief throughout this process and are uplifting, which must be good—in and of itself—for my body.

Meditation As I said in my last email, meditation has been extremely important in dealing with the night owl syndrome. It was, however, initially difficult to sit in the mornings. No matter how many years I keep practicing, there are times when trying to quiet my mind is about as impossible as herding cats. It was especially difficult as I began to deal with the fact that I had cancer. Once I sat down, I could not take refuge in the constant and easy to find distractions of life. It wasn't despair that blindsided me —that emotion is not in my cancer vocabulary—it was the constant questions: "what if…," "how can I…?," "what will the future hold?," "am I strong enough to deal with this?," and worries about my family. I slowly began to realize that none of these questions have answers.

Meditation allowed me to let go of the need for answers and simply be. It transformed the phrase of "living in the moment" from a series of words strung together and a wish of how to live life into an action. I know, this phrase of "living in the moment" is overused, thus threatening the critical importance of what it is supposed to

convey. Let me tell you what it means for me right now. It means laughing with my sisters and Mom in the face of fire diarrhea, going out kayaking when my stomach already feels seasick, taking my Dad out for a special Father's Day dinner during a treatment week, hearing my brother's voice on the phone, spending time with my friends on my back deck, and even playing fetch with my cat.

As a cancer patient, living this phrase is actually easier for me now than when I was completely healthy. The sensations going on in my body from the chemo constantly bring my mind back to the here and now. In some crazy way, it is almost like I'm more alive: my taste buds are heightened, I fully realize how bad I feel without enough sleep, and simple things like going to the bathroom have taken on new meaning. All of life's basics have become much more poignant and reinforce living in the moment.

Acupuncture Now, if you are like my brother, you will be cringing at the thought of acupuncture and hurriedly skipping to the next section. That was my first reaction too, because, believe me, I most certainly don't like getting stuck with needles. If, however, acupuncture was in any way similar to the way in which I have been repeatedly stuck during these past three months, I wouldn't do it. In contrast, the acupuncture needles are so thin (and Erica so skilled) that I rarely feel them. You may therefore be wondering why and how I have been getting acupuncture for over seven years. I began acupuncture as a possible way to avoid having another fibroid surgery. However, what I found was not a shield, but a wonderful teacher, listener, and magician. My body simply seems to soak up the effects of the treatments. I feel a difference almost in the very way my blood flows. I don't know why and I won't pretend to be able to tell

you how it works. I'm simply a pragmatist—the only proof I need to continue something is to have it work. And it does, wonderfully!

Erica has been a godsend since this journey began.[12] I try to see her for an acupuncture session at the end of each treatment week. During a session, I fall softly and deeply into a thought-free, blissful state of relaxation. The effects continue long after Erica has departed; my bodily functions—an obsession for cancer patients—seem to operate much more smoothly. The other benefit is the comfort that it brings mentally. When she checks my pulses—which is how she tells what my body needs—they are strong, despite the chemo. It is reassuring to know that through this 4,000 year-old practice we can tell that my organs are doing fine and are enlisted in the fight against the disease. I also feel that the acupuncture is akin to giving them, and my blood, a warm soothing bath so that they can continue their work. If you are under stress or have an ailment, I heartily recommend that you give acupuncture a try!

Speaking of Needles While I decided to give up educating myself on all aspects of cancer, I remain steadfast in my determination to seek out avenues of support through the treatments. I therefore went to a homeopathic doctor who has been treating cancer patients for over 30 years. I was interested in any natural healing remedies that he might have to support my body as well as suggestions on diet.[13] I was awed by the vast knowledge of this doctor. It seemed that he had studied and read every book on cancer. Every question I had, he answered easily.[14]

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[12] Erica Lazaro is a wonderful acupuncturist who can be found at 8830 Cameron Street, Suite 501, Silver Spring, MD 20910 (301)565-2700.

[13] By the way, consistent with my philosophy to have fun along the way, my dear friend Dar took off the day to drive me to Baltimore to see him. We made a day of it; we had lunch after the appointment and even spent a bit of time at the phenomenal Walters Museum. It was a great day, filled with laughter.

[14]This doctor's name is Dr. Peter Hinderberger and his details are as follows: General Practice, Homeopathy, & Anthroposophic Medicine, 4801 Yellowwood Avenue, Baltimore, Maryland 21209 Phone: 410-367-6263 Fax: 410-367-1961

I came away with a variety of recommendations for supplementing my treatment. The most interesting was injections of mistletoe. Apparently, mistletoe has properties similar to chemotherapy and it supports the immune system. The fact that I had even entertained the idea of giving myself daily injections attests to my seriousness of beating this disease. I stood in my kitchen with the inch long needle pointed at my belly. The pep talk began. "Come on Lindy, it is just a little needle. It won't hurt. You have so many people supporting you, the least you can do is face this little needle." I'd make a motion to stick it in, then actually jump back from it (it would have been hilarious to watch). It took me over 15 minutes before I finally managed to gather enough courage to stick myself. Although I felt sick to my stomach (released fear no doubt!) for the next 15 minutes, I kept up a constant stream of mental chatter about how it wasn't so bad. I was preparing myself for the injection the next day.

Then again, I hadn't counted on my control freak oncologist, Doc Mary. She wants to know everything (with the exception of food) I put in my body, including vitamins. I had told her that I was going to see a homeopathic doctor and, after slightly raising her eyebrow, she told me to check in with her on his recommendations. She vetoed the mistletoe. My body is at the limit of its ability to handle chemo and she didn't want me having anymore, natural or not. I must admit, I did release a sigh of relief… .

You are what you eat Many of you have so kindly offered or made me things to eat. My appetite, as any cancer patient will tell you, has been here and there and mostly nowhere. For 10 days following a treatment, I can't eat or drink anything cold. Sometimes hot food doesn't appeal either. Although I love spicy food, these days my stomach doesn't. And then there's the milk issue—chemo first causes constipation

followed by diarrhea. It's just a simple, unfortunately unavoidable fact. This week, I learned the milk lesson: don't drink anything with milk when diarrhea threatens. (Warning: you may want to skip this discussion) I got terrible chemo cramps on Friday. I called Doc Mary's office and the reception had the doctor on call return my call in under two minutes. Unfortunately, there was nothing he could do except sympathize about my cramps. Diarrhea wracked my body and left me weak. Thankfully, I was eventually able to pass an uneventful night and actually slept soundly.

The next morning, however, it returned with a vengeance. I had ignored the lesson about not drinking milk during the diarrhea phase and had tea with milk in it. As I stood there in the airport, waving goodbye to Monique, the diarrhea returned before I could get to the bathroom. Time seemed suspended. I stood there, feeling like I was watching this happening to someone else. My brain seemed to fail to grasp the essence of the situation and all I could think was "well now isn't this interesting." When my brain finally kicked into gear, I tied my jacket around my waist and waddled slowly to the bathroom. I didn't cry, I didn't even get embarrassed. I simply acknowledged that cancer sucks and that I had truly reached a new, all-time low.

I have been trying to figure out how to handle my diet. It's made more difficult, of course, by the fact that I will not listen to my brother's advice and go "back on the cow". A friend sent me some suggestions on eating from Sloan Kettering, but I was still searching. Doc Mary's only advice was to call the dietitians at the hospital, but they didn't have any solid advice. The homeopathic doctor advised an alkaline versus acidic diet. I didn't see too much of a difference between that type of diet and my usual diet, except to avoid certain foods. I then researched a macrobiotic diet, which is primarily

grain-based. The dietitians, however, advised against it, because it lacks certain nutritional elements and advocates a more limited fluid intake.[15]

I finally landed on what I call the "LaCas Diet," named after my friend Monique, which combines her diet with suggestions from Sloan Kettering. When she was here last week, we ate foods that were as fresh as possible (some straight from my burgeoning garden), a bowl of fruit with flaxseed and blueberries every morning, good olive oil as a key ingredient, goat cheese in limited quantities, and as many vegetables as possible. It works. I didn't have to take the awful laxative during the constipation phase of the treatment and I felt great. Now it's just keeping it up!

Monique, my bonne amie, who helped me heal with her love and cooking!

To many of you, I know that some of these alternative healing techniques may seem weird, new agey, and something that you may only be exposed to in the media and now by this email. Perhaps now, however, just one of you may be enticed and open to

[15] I strongly encourage all cancer patients to do their own research on the issue of diet and make your own decisions about whether to follow a macrobiotic diet. Some people believe a macrobiotic diet has cured them of cancer. I also strongly advise patients to experiment with what foods make them feel best. While obviously certain foods are better for us than others, each person's body is different and different foods may be more appropriate for some than others.

the possibility of including some of them in maintaining your own health. Whatever technique you use, eastern and/or western, please be sure to listen to your body and act on the messages it sends.

Thanks for listening,

Lindy

Across the Pond

"When a man is tired of London, he is tired of life."
Samuel Johnson

Hi all—On July 13, I boarded a plane for London. As I buckled my seatbelt, I pushed away the last minute thoughts that what I was doing was crazy. I had a doctor's note saying that it was okay to go and, since I had just received chemo in the morning, I wasn't going to miss any treatments. I pulled on my socks, my hat, and my blanket. I had taken every precaution that I—and anyone else—could think of to safeguard against getting sick. With a sigh, I pulled out my blue facemask. Imperceptibly, I felt the woman in the seat next to me try to shift farther away and not stare. Undoubtedly, she had not expected any blue-faced clientele in first class! I could tell that she was intently not watching as I pulled out my pill bottle to take the wonderful anti-nausea, makes-me-sleep pill, Ativan. I briefly toyed with the idea of putting her out of her misery by telling her not to worry that I wasn't contagious and that it was just cancer, but I wasn't sure if this would result in killing conversation or starting one. Since I wanted to sleep, I let it go and closed my eyes.

Why go? Some of you who knew I was traveling to London were concerned. For me, although I admit to having a few errant moments when I wondered whether I could physically and mentally do what I knew needed to be done, it wasn't a question. There were so many reasons to go and so few not to do so. One reason that I have only begun to appreciate fully now that I'm back in the States is that this trip gave me a goal to

work toward and it provided a respite from the otherwise long days where the focus is on my disease and not my life's passion. It also marked the important halfway point in my treatments.

In a way, this trip was the conclusion of the first part of my cancer journey. The primary issue that called me to London was one that I had been working on when I received my cancer diagnosis. The issue, for those of you who are not working with me or have not had to endure my endless chatter about it over the years, is the designation of certain areas of the oceans as Particularly Sensitive Sea Areas (PSSAs) by the International Maritime Organization (IMO), a Specialized Agency of the United Nations that addresses international shipping issues. The IMO had decided to revise its guidelines for PSSA designation and I was leading a very active correspondence group working on the revision. Although it was a lot of work over a six-month period, leading the correspondence group was fun. I had email pen pals from all over the world and even those who would call from time to time. Issues were brought up and discussed that teased and tugged at my brain. Jokes were told, friendships formed. The guidelines document grew from 15 pages to over 100 and then back down again to just under 40.

With the submission deadline of April 15, I had been working fast so that I would have ample time to perfect the document. That plan came crashing down on my head on March 29th. I had one section left in which to integrate everyone's comments, the cover note to draft, and four days until surgery. My sister Nesa, who has uncomplainingly listened to me talk about the PSSA issue for almost 13 years, asked me what I wanted to do over these four days. She asked, but she knew. She cleared the decks for me, handling all the calls, the groceries, and the details of my life while I finished the

document and handed it over to my boss to proof-read and give to the Coast Guard for submission.

I imagine at this point that some—or even many—of you are shaking your heads. After all, what would you do if you had four days before surgery, had just been diagnosed with cancer, and were faced with the choice of finishing a work project or just living your life? I knew that no one would blame me if I didn't finish the work, so why did I make the choice I did? There really isn't one answer to that question. In part, I couldn't escape what is engrained into my very personality—I was brought up with the value of finishing what you've begun. It was also because Nesa and I knew that I would rest more easily knowing that this job was done. And then there was the question of comparing this peace of mind with the choice of doing other things. What "other things"? Any type of carefree, lets-go-to-the-movies existence had been taken away. We couldn't leave and go to the shore, because I needed to get fluid drained from my lung. So, perhaps part of the answer is that thinking about PSSAs and racing against the clock to get the document done allowed me another two days of respite from dealing with the inevitable.

Another reason that I found it easy to go to London is who was there and who was going with me. As most of you know, I lived for a year and a half in London and was one of the first IMO interns. I thus have many friends who work for IMO, but in particular two, Rouba and Alfredo, who I knew would be there for me if anything went awry. These two, simply put, are family. Even though we literally look as different as night and day (and to her exasperated amusement), I introduce Roubs as my sister. On the weekends following IMO meetings, we spend time chatting and catching up on life.

This time was no different, although there was a new topic on the table. While we thankfully did not dwell on my cancer, Roubs—in her usual big-hearted and straightforward manner—brought up questions and issues that I'm still thinking about today. As for Alfredo, his generosity and caring knows absolutely no bounds and he was, and always is, there for me.

Alfredo, me, and Rouba

Additionally, lucky for me, two of my dearest friends were also on the U.S. delegation. All three of us have been attending IMO meetings for several years and have become habituated to staying in certain hotels; we know such things as where the nearest Indian or Lebanese restaurants are, the store at which to buy the International Herald Tribune, and how much time it takes to get to IMO. When they heard I was going to London, Bry and Kathy did not hesitate to abandon their comfort zones to stay in the same hotel as me, near IMO. At the end of each day and chatting all the while, one or the other would simply pick up my loaded briefcase and carry it back to the hotel. It was such a comfort to know that they were only a phone call away if I needed them.

I also knew that I had the support of so many others at IMO, from my international friends to the others on the U.S. delegation. No day passed without one or another of my U.S. colleagues asking me how I was, offering their help, and just providing a word of encouragement or understanding as the week progressed. As for my international colleagues, some knew about my cancer diagnosis and some did not. For those who did not, it was freeing—I was normal and not sick. For the dear friends I've made along the way, they knew. How could I not share this news, when we've shared so many other things as we worked together negotiating conventions, protecting the oceans, and facilitating the environmentally safe movement of ships? Our lives over the years have become intertwined beyond the strictures of work issues and I am truly honored by these friendships. Even though I had to conserve my energy for the issues before me and was not able to spend time catching up, I drew strength and support from the very fact that they were there.

Day by Day I would be lying if I said I faced the week at IMO with equanimity and no feelings of trepidation. This cancer journey still fits like a bad suit and, although I generally feel fine during the "non-cancer/chemo" weeks, I was unsure whether there would be any adverse effects from this complete disruption in my life. There were nights in London when sleep simply evaded me even after I broke down and took sleeping pills. There were also new sensations to keep me grounded in the reality of my disease. A metallic taste remained on my lips, the tip of my tongue, and in my mouth for a long time after the treatment. The chemo also seemed to hang on my skin, almost as if I had walked through a cobweb that couldn't be dislodged. This cobweb, however, carried with it a soft tingling feeling which reminded me of the time as a kid when I'd backed

into an electric cattle fence. And throughout it all, there was that constant thud in my brain when waves of tiredness simply washed over me.

Despite these lingering sensations, I could not have scripted a more successful conclusion to this meeting. In saying this, I must acknowledge a long standing belief that no one person is indispensable with regard to work issues and therefore do not believe that it was my attendance alone that made this conclusion possible. It was a matter of teamwork, hard work, and the creation of a spirit of cooperation that yielded this result. One of the most important ingredients for success in international work is continuity in representation, the relationships that are built because of that continuity, and being able to set in place the elements necessary for success even to be possible.

In the PSSA scenario, a key player was the chairman of the Committee, Andreas Chrysostomou from Cyprus. I had asked that the PSSA issue be addressed first so that we could finish; I also knew that I did not have the stamina to work the usual, incredibly long IMO hours. Andreas also agreed to have the Committee make a number of key decisions that greatly facilitated our work. True to his word, he had the Committee address PSSAs on Monday and a technical group was sent out under my chairmanship to finalize the guidelines and draft resolutions to designate four areas as PSSAs: the Galapagos (Ecuador), the Canary Islands (Spain), extending the Great Barrier Reef PSSA to include the Torres Strait (Australia/Papua New Guinea), and the Baltic Sea (the surrounding States with the exception of the Russian Federation).

We started work on Tuesday, with about 50 participants. Wherein previously I have always found it easy to listen simultaneously to a discussion, draft a solution to an issue, and think about how to handle the next issue to come, at this meeting—even

though I managed to do this a few times—it was hard. There were also times when I felt that I just wasn't as quick as usual to pick up on a point. While I've been told that this wasn't at all noticeable to others, it was noticeable within the four walls of my own brain and there were a few times that I could almost hear the click! whirr! as my attention seemed to falter momentarily then reengage. Notwithstanding my own participation, there was more than adequate expertise in the group to assist me. My own delegation, the font of IMO history and "friend of the chair" Joe Angelo, my dear friends from New Zealand and World Wildlife Fund for Nature, and others ensured a full discussion of the issues and facilitated the conclusion of the guidelines. For my part, I tried to guard against any possibility of my shortcomings by planning ahead, putting together draft language on outstanding issues ahead of time, and keeping the discussions moving.

To everyone's surprise, we finished the discussion of the guidelines by noon on Tuesday. I breathed a sigh of relief. I had pushed the group hard (perhaps a bit too hard at times), but we had been given a task to do and I did not want to fail the Chairman or the Committee. Moreover, I will admit that at the back of my mind, there hung a cloud of fear that my health would—for some unforeseen reason—falter and the successful conclusion of the guidelines be placed in jeopardy.

After the guidelines, we went through the four individual PSSA proposals. Things were going quite smoothly until we sailed into the Baltic Sea. Two sessions ago, the Committee had designated this area as a PSSA "in principle" and Russia had objected. The delegation continued to voice its objections at this meeting and continued to do so—quite vociferously—for over an hour and a half. I questioned, prodded, parried, and finally overruled its suggestions to amend the Committee's decision.

Although I had a four piece drum set playing in my head at the end of the day, I pulled up a chair across from the Russian delegation and told them quite bluntly that I couldn't understand their problem. Around and around we went again when finally enlightenment dawned. Once we understood the problem, my expert Coast Guard drafter and I devised a solution. We held our breaths as the delegation discussed it in Russian; our eyes would turn to each speaker as if we could follow their conversation when, of course, not one word was understandable. Finally, both Sweden, representing the other Baltic States, and Russia said that it was acceptable, but that they needed to get clearance from their capitals. I would have been elated if I hadn't been so tired. It had been a long day.

The meeting ended with a bang on Friday. Despite some grumbling from key delegations about the guidelines, the Committee approved and forwarded them on to the Assembly for adoption. We then came face to face with the Baltic Sea proposal. Moscow had rejected our solution and once again, Russia railed against designation. Wherein previously they had been isolated, it was clear that they had been working the room and had gained at least a dozen States in support. The Committee broke for tea and the Chairman asked me whether I would be willing to try once again to broker a compromise. A small group went out and, glory be, a solution was developed. The Committee adopted it and, as it turned to the next agenda item, I got up from behind the U.S. card to go to the back of the room. However, Russia was not yet finished and the head of delegation insistently rapped his country card on the table. They had a point that they insisted *must* be inserted in the record of the meeting. My last drop of adrenalin had been spent. What could they possibly want now?! And then I listened. It was another lengthy intervention, yet this time it was extolling and thanking me for my efforts. I

stood caught like a deer in the headlights as one of the delegates brought over a beautiful bouquet of flowers. They concluded with a simple statement of "we love our Lindy." I was so taken aback and humbled. I said something in response, but I don't remember what it was…I just hope it made sense and conveyed my feelings appropriately.

A friend asked me whether I thought that people helped me at the meeting and whether the Russian's response at the end of it was because people knew I had cancer and they felt sorry for me. I honestly don't know how far the word of my disease had spread. I do know that although bad news travels fast, many people at this meeting did not know. Those who did were there, supporting me, giving me words of encouragement, and helping in any way they could. Would the results have been different if I didn't have cancer? Perhaps Andreas may not have addressed the issue on Monday or allowed so much time to be spent on it; whatever the reason for this help, I am truly grateful. I guess I'd like to think that what happened at the meeting had nothing at all to do with me and whether I had cancer or not, but everything to do with the issue itself and the hard work that the correspondence group put into it.

Yet even as I think about this question, I wonder, does the answer to it make any difference? People worked together, in spite of some deep divisions in opinion, and we even had fun in doing so. It could perhaps be that the manner in which people worked together was another one of those cancer gifts. I have found since starting this journey that there seems to be more respect, more patience, and, for a lack of a better way to say it, a recognition that we are all human and can make mistakes and have bad days. While I'm sure that this will bring smiles to the faces of some of you, I am willing to admit to being rather persistent (some would say stubborn), opinionated, and sometimes even

downright disagreeable in my pursuit of NOAA's position. Cancer may have caused me to mellow—no, not in my ardor to protect the oceans, but in how I go about it. I have realized that I don't need to hold on so tightly to each aspect of an issue but can allow others room to work without jeopardizing—and, on the contrary, even enhancing—the ultimate outcome. Perhaps this new attitude was subtly felt by the group and had an impact: yet who knows and really who cares? I would rather not focus on any role that I may have played—it isn't important at the end of the day—what is important is the long lasting benefit that the meeting achieved in providing protection for the oceans.

Aftermath I arrived home late Sunday night from Hogwarts (yes, the new Harry Potter book kept me company all the way home) and went in for a treatment on Monday. I'll be blunt. I've had a rough time since my treatment. All the side effects seem to be magnified, my sleep is still disrupted, and I haven't bounced back as quickly as I have come to expect. Each day, I simply hang on to the belief that tomorrow will be a better day. In my grumpier moments, I line up a list of things that may be contributing to this prolonged adversity. I shake myself quickly, because such an attitude truly doesn't accomplish anything. It is what it is.

It is still hard to believe that cancer now plays a central role in my life. After all, I was supposed to be hiking Kilimanjaro today—I even closed my eyes at different points throughout the day and tried to will a different scenario. But life doesn't work that way and I am disappointed. Yet again and with a shrug, dwelling on my disappointment gets me nowhere. Therefore, throughout these past days, by sheer stubbornness and force of will I have repeatedly forced myself to count my blessings: I'm still here, I've had some

great times these past few months that I wouldn't trade for anything, and, with surprise and gratitude, I accept the gifts that cancer is providing along the way.

As always, thank you so much for listening, be well,

Lindy

Silence and Selfishness

"Nothing endures but change."

Plato

Hi there—I just finished my fifth to the last chemo treatment, so I'm two-thirds of the way done! Yeahhhh! This one was important to me. I explained it to my family and a few friends in this manner. When you are singing the 12 Days of Christmas, you reach that crescendo, grandiose phrase of "FIVE GOLDEN RINGS"! Then there is a poignant pause before the song just seems to trip and fall over itself to its conclusion. That is exactly how I'm viewing my last four chemo treatments…although I don't intend to trip and fall but rather skip (at least mentally) to the end.

October 5th is the day I have marked on my calendar to receive my last injection. My wonderful, control freak doctor, however, is more cautious. Just as with many rites of passage, I will have to pass several tests before she agrees that there is "no evidence of disease" and thus no more injections are necessary. These tests include blood tests and a "PET" scan, which is an injection of radioactive dye into my body in order to determine whether the cancer is under control and whether there are any tumors growing. While there is little more I can do at a physical level to prepare for the tests, I believe that the mind/body connection is strong and therefore I still have work that I can do in visualizing and believing to my very core that I am healed.

Silence A friend recently asked me why I was being so open in talking about my cancer. She seemed worried that because I have been so frank about some of the details that people may laugh at me or perhaps think differently about me in the future. I

brushed off the thought that people would laugh at me and, as for thinking differently about me, well, I cannot deny that even I think differently about myself now. Cancer has a way of breaking down how we view ourselves, our relationship with our bodies and what they mean to us, how we pursue our health, and even our relationships with other people. Every aspect of life is examined and reexamined first to determine every possible way to avoid the reoccurrence of cancer and then slowly, at least for me, there has been a release of worrying about the things that heretofore I tried so hard to control. I have come to a more general acceptance of myself, my situation, and others.

But my friend had a point. How and why do you tell people that you have cancer? Although it is now a given fact that I have cancer and you may not even recall how you found out about it, I will admit that at first I couldn't tell people. That was, of course, because I wasn't admitting it to myself. I did, however, tell each of my family members. I shudder when I think of how I gave them the news; I remember delivering it more as a statement and without a full appreciation of the rocking sensation that I was sending through their worlds. Lucky for me, they are a stalwart group and, instead of me having to handle their fears and upset at the news, they rallied instantaneously. It is at times like this when I am awed and so very thankful for the family that I have.

When Nesa and I rode home from our first visit with the oncologist, we decided —very logically—to split the list of people I wanted to call in two: she would call one group of people on her cell phone and I would call the others. Well, I managed to call only one person. I heard myself say the words and the cancer threatened to become real. I wasn't ready for this and therefore just couldn't bring myself to say the words again and again. Perhaps part of my reticence was because I am a coward. I could barely sort out

my feelings about having cancer and therefore I wasn't prepared for dealing with others' reactions to it, especially when people were so unprepared for such news. I broke down in tears after my first call and thereafter left all of it—for the next month and more—to Nesa. I don't know how she did it, but she did, day after day. Many of you then in turn set up your own little phone trees to contact the people you knew I would want to know and blissfully, this responsibility was taken from me.

My rock, my Nesa

So what about now? Although a good many people know, I don't stop strangers on the street to tell them I have cancer. I must admit I struggled for awhile with the question, "how are you?," from people that I know, but see infrequently. I have never been one to ask or answer that question lightly and cancer has only highlighted this dilemma. I mean really, why do you ask a grocery store clerk how they are unless you

are going to look them in the eye and care about their answer? Is it just to fill space? Is it merely a useless banality of our society? With so much fragmentation and isolation in today's world, to me this phrase—delivered and received in a caring manner—strengthens the bonds among people and simply shows respect for each other. So, for the most part, when asked this question, I have answered it with the truth. Unfortunately, the answer can be quite a dramatic conversation stopper! So, I've tried out many ways to deliver this news, from the casual, having-a-great-summer-in-between-chemo-treatments, to following it up with bad cancer jokes, to simply stating it as a matter of fact and then dealing with the person's reaction, whatever it is.

The next question is, why tell people? In one of my first emails, I said that if talking about it helps even one person understand this disease and what cancer survivors are going through then it serves a purpose. I still believe that; however, I have learned a lot since that time. No cancer is the same, the treatments and side effects are very different, and people have varied reactions. It may thus be then that my story does not help in any way to understand truly what someone is going through with cancer. And yet, I'm not sure this generalization is right either. There are some similarities among cancer patients, such as getting radiation and chemotherapy are truly unpleasant; those going through treatment will more likely be tired, nauseous, and have "bathroom issues"; there may be similar questions with regard to diet, exercise, and alternative healing therapies; and all of us in the cancer community eventually have to wander through the broader existential questions.

After rethinking it, I decided to continue to share with you and others my cancer journey in person or via email. Email, while at times annoying by its sheer volume, is by

far the easiest way to communicate and it has been a perfect medium for me during this stage of my life. It has satisfied my compulsion to write, it helps me sort out my own thinking about this disease, and gives me peace to sleep. I also continue to feel bad that I simply do not have the energy to talk to everyone who calls or writes to give me support. At least by email, I hope to let you know how much I appreciate this continued support. Another motivating factor for my writing is that I want people to hear of my journey from me. I don't want people feeling sorry for me. Only positive energy and an upbeat attitude will see me through to whatever conclusion my life is supposed to reach.

There are more general reasons to share stories about having cancer. I believe strongly that by raising the consciousness of people about cancer there will be more of a demand for a cure and that, selfishly, will benefit me as well as others. It also may help people to realize how many people out there are—or have—squared off against this disease. Additionally, perhaps my story will encourage some of you to be proactive in walking or running in the race for the cure or some other event that focuses on obtaining a cure for cancer or some other life threatening disease. I would also strongly encourage you to be vigilant in getting your cancer detection tests (*e.g.*, colonoscopies, mammograms, and the tests for prostate cancer) so that you can avoid having a story like mine.

Setting aside these seemingly more lofty, general goals, perhaps the only real reason to talk about this disease is because it shows just how frivolous life can be. Here I am, a vegetarian, someone who exercises regularly, and I'm not yet 50; I had none of the risk factors for getting colon cancer. So, do I stop and say "why me?" No, because that could mean that I think someone else should have gotten it and I would never wish cancer

and its side effects on anyone. To acknowledge that I—an otherwise insanely healthy person who has been practicing a healthy lifestyle for years—have cancer is to recognize the random nature of life. While we can control some things, many things we cannot. This, especially for those of us who like to imagine that we can control things, is truly liberating. Faced with the reality of my disease, I am therefore left with the simple fact that the only things I can control are my attitude and how I treat other people. If I can just get these two things right, then everything else will follow as it should.

There are some definite drawbacks to telling people I have cancer. Some people don't react or don't react well. By talking about it, it also keeps it as a focus in my life (of course, right now, it is almost impossible for it to be otherwise!). The other potential drawback is what I have taken to calling the "Cancer Pass". This is what the "Cancer Pass" provides: you get a "pass" on having to fulfill your normal obligations because you have cancer. While there are limitations that accompany the disease and its treatment and therefore some accommodations are a physical necessity, I am very careful about using this "pass". I don't want this disease to become a crutch or disability, and have yielded to using the "pass" only when necessary. For instance, as a silly example, I went to park in the underground parking near my building the other day, because when I walk any distance in this extreme heat my body feels like it becomes a cauldron of bubbling chemicals and thus I feel quite ill. There was only valet parking left and, when I told the attendant that I would be leaving work when I got tired, he actually smirked and told me that it must be nice to be able to leave when I felt tired. I inwardly groaned when he said that; I had no choice—it was use the Cancer Pass or be blocked in and unable to leave. I used it.

In concluding on this topic, there is another reason for telling people about my cancer. It has created a bridge with people that might not have otherwise been there. It has also opened communication with people such as my wonderful cousins and others who are part of my history and life, but who were not present on a day to day or even month to month basis before this. Finally, sharing my story with many of you has underscored that I am not walking this path alone, but thankfully you are with me. That in and of itself is reason to talk about it.

Selfishness Several years ago, a Vedic astrologer told me that the one constant in my life was change. Seeking only stability and no more change, this was the last thing I wanted to hear. If, however, what he said were true, I knew I needed an attitude adjustment. Therefore, I began to look for things to appreciate change: the fall colors, a caterpillar turning into a butterfly, the stars coming out at night, and the arrival of the fireflies in June. These things were, of course, easy to accept because they do not result in any major upheavals in my life. Nevertheless, whenever a change was occurring that I didn't particularly like, small things like these helped me to accept the change….until the last two weeks.

There have been several changes in my life during these past two weeks that I have not accepted readily or happily. One of them, in fact, was so important to me that I could barely talk about it for the last month without tears welling up in my eyes. Family and friends, worried that the stress of this change would affect my health, tried to point out reasons that the change might be good or to jolly me into a good mood about it. While I generally condone looking at things with a positive attitude, applied indiscriminately, it leads—in my opinion—only to a pollyanna-type of person and

questions about whether there is any depth of emotion about anything. This simply is not me. I therefore had to take time to mourn and work through these changes in my own time.

I started, however, from the point of view of pure selfishness. Why did these changes have to happen now when I am at my most vulnerable and least able to adapt to new situations? I was surprised at my self-centered thoughts and comments as I demanded to anyone who would listen that they not make any more unnecessary changes until I got through my chemo treatments. I just couldn't handle anything more. Lucky for me (and everyone around me), I was listening to myself as I spoke. I realized that despite the cancer, the world doesn't revolve around me. Change, like the tide, is certain and, if I didn't come to grips with it, it could pull me under in a wave of despair. I had no choice but to work through the changes, cry as much as I needed to, and then accept my new reality.

The change that was the hardest for me was the retirement of my boss and wonderful colleague, Karen. I walked into NOAA General Counsel's Office of International Law 13 years ago and she literally greeted me with open arms and hug. It was, for me, a match made in heaven. Although I had worked in a Wall Street law firm with supposedly some of the best and brightest, Karen was by far and away the smartest attorney with whom I've had the pleasure of working. She combined the ability to parse through thorny legal issues, with that of keeping sight of broader implications and mastering the most minute legal theory and principle. After I would regal her with detail after detail about some issue, I would be amazed to hear her succinctly summarize it in a few sentences. She expertly guided my boundless energy and passion into the proper

channels and, by backing me up and supporting me, let me soar. Karen has made a quantifiable difference in the oceans and the lives of those of us who surround her. With these words, I dedicated my book, *Coastal State Regulation of International Shipping*, to her,

> There is one person who—while being an incredibly bright and forward thinking international attorney also has the utmost respect for the rule of law and practical considerations—has been an inspiration and is responsible for guiding my thoughts in this area into deep and deeper channels. For all of us who love to walk by the ocean shores, listen to its crashing waves, and enjoy its creatures large and small, we owe a debt of gratitude to Karen Davidson.

Even more than the impact Karen made on my life professionally, she served as my colleague, friend, and moral compass. Day to day, she embodied living life with the highest of ideals and frequently caused me to pause to remember those things that are truly important in life. She was there giving me strength (and letting me cry) as I struggled through such things as relationships, my first fibroid surgery, and then, of course, this cancer trip. Through it all was her warm hugs, quick smile, ready laugh, and wonderful cooking!

Kate (Karen's daughter), Karen and I at a party for Trina and her Washington D.C. area friends. It was June, one month into chemo.

I don't pretend to be able to do justice to one of the most important relationships in my life in a mere few paragraphs. Moreover, Karen—being one of the most self-effacing people I know—is probably stricken to read even this paltry tribute. As I moved away from my selfish attitude about having Karen leave the office, I began to redefine the change as one not of an ending but as a new stage in our friendship. For her, I want only for her to be happy and to spend time doing things she loves. For me and my life in the office, I am focusing on the sentiment that with uncertainty there is always hope. Additionally, I long ago learned that when adversity appears, there is also a great opportunity for learning and some amazing things can occur. I am also counting my blessings that at least for 13 years I had an incredible boss and colleague who left an indelible mark on me professionally and personally. I will miss her in the day-to-day operations of the office and yet I know that she and her family will always firmly remain a part of my life.

Two other changes are occurring that are not necessarily to my liking, but which I have come to accept (since I don't have a choice!). First, while I was in London, I was confronted with the news that my Dad had decided to sell our cottage in the Upper Peninsula of Michigan. Already trying to deal with the change of Karen's retirement, I reacted quite grumpily. Not one to accept only a surface explanation, I immediately began to fret about the reasons for this decision. He loves this place more than any place on earth; why, then, was he selling it? Was it because with all this sickness in our family he was looking at his own mortality and accepting it? This thought was unbearable, so I quickly shied away from it. After a couple of days of getting myself completely worked into a tither, I spoke to Dad. Wow, sometimes life can be simple! He was happy with his decision, he sold it to my cousins who also absolutely love the place, and, without the cottage, he would be free to travel wherever he wants to in the Upper Peninsula. I breathed a sigh of relief. Okay, if he was happy, I would be too.

The second change is that my dear friends Leila and Daniel are, after long last, leaving Washington. While I will miss them, this change I find a bit easier to accept. They are moving to San Francisco to pursue their dreams and are so very excited. As I said goodbye today, their enthusiasm for life was infectious. They are moving on, embracing life with an open attitude for its possibilities, a sense of adventure, and broad smiles. As we said our goodbyes, I mentally reminded myself to remember the joy with which they were greeting change.

I now accept that my life is, after all, about change…even though it now feels like I'm only treading water until October 5th. So, yet again, cancer has provided me

with another valuable life lesson: Be wary of a selfish attitude toward change and, even if it takes some time, embrace it.

As always, thanks so much for listening,

Lindy

Drugs and Money

"If you think you are not rich, just count all the things you have
and the people in your life who bring value to it.
Money can never buy that."
Randy Watson

Hi all—Depression is insidious, it invades your body as completely as an odious smell on a warm summer breeze. Feeling bad day after day, the sleepless nights, and the constant shadow of nausea are taking their toll. It has been hard these past few days to be civil even to loved ones and, after I realized that I've just snapped at them for no reason, the spiral downward accelerated. Then came the news of two people who died of cancer; I didn't know them personally, but the news assailed my tower of belief that one doesn't have to die from this disease. Despite my pep talks and attempts at distraction, the pity party just seemed to grow louder. Uncharacteristically too, I frittered away an entire day, doing basically nothing but reading now and again—it may sound nice, but to me, it was only a depressing reminder of how I felt. My energy was low and my spirits sagged.

My mind wandered and raged. I don't understand what is so magical in the cancer world about the number 12. After all, I have now completed nine treatments, why can't nine be that magic number? Nine is special in yogic lore, so why not in the cancer world? On a rainy, gray Saturday, I knew that I should be elated that I have only three treatments left (hopefully) and, most days, I am. The times when I actually feel good, however, are beginning to seem so far apart. Was it only last Saturday that Karen, Mike and me spent a wonderful day paddling and in the afternoon I laughed at the antics of

little one-year old Mateo? I make those memories to help me through these interminably long days following a treatment and yet there are times when the memories seem so distant that I can hardly believe they happened at all. These are the days when I curse this disease and its effects. Impatiently, I tried to shake off my foreboding negativity. I vowed not to let it get the best of me and relegate me to whining and complaining. My constant mantra during these times is, "tomorrow will better, tomorrow I will feel better." Until that occurs, I'm distracting myself by writing to you.

Window on My World I told Nurse Kristen several weeks ago that I felt like joining the U.S. Olympic Swim Team and that I'd been going to the gym and lifting weights. Familiar now with my sense of humor, she knew I was joking, but not sure why or about what. I had found out that one of the drugs they have me taking is Decadron, a steroid. My nephew is taking massive doses of it to shrink his brain tumor and my brother told me that it was a steroid. Nurse Kristen thought I knew this, but with all the things they told me at the beginning, it is no wonder I didn't focus on this fact. Given the controversy surrounding steroids, I promptly told her that I was going to stop taking it. She—and Doc Mary—did not abide by my purported decision for one second.

Apparently, in the cancer world, Decadron serves many purposes. It shrinks any tumors that might start to grow, fends off nausea, and helps maintain your appetite and weight. As with all of these drugs that I'm taking to address the side effects of the chemo, Decadron has its own side effects: it disrupts my sleep patterns, causes painful constipation, and results in hot and cold temperature differentials. Oh joy. Luckily, however, I haven't (yet) noticed any defined squaring of the jaw or massive biceps building.

While a few of you have had a ringside seat in my day-to-day existence over the past several months, I thought I would take you through my treatment week. I have to say, there is no "typical" treatment week; some are better than others and the effects curiously vary. The drugs and treatment regime, however, remain depressingly the same. I continue to be amazed by my body's resiliency. This is no doubt due to the fact that, other than the cancer, I am healthy and will continue to insist on this in my lifestyle habits, mental attitude, and physical well-being.

Most Mondays of treatment week, I am in my office in the morning. It provides a measure of normality to my life and keeps my mind from dwelling on what is to come. Around one o'clock, my beloved caretaker for the next three days and I leave for Doc Mary's office. At this time, I have to apply Emla Cream to my port so that it numbs the area. Unfortunately, during this last treatment, I did not apply it in time and felt the three-quarter inch needle penetrate. (You may think that because I get acupuncture that this size of needle wouldn't bother me—on the contrary! I hate any size of needle and never ever look when Erica is applying her magic acupuncture needles.) I also take my first anti-nausea drug, Emend. This drug is as good as gold in both action and cost: I haven't thrown up since I started taking it and, to my shock, it costs $100 per pill.

After having my weight, blood pressure, and temperature checked, we are sent to a private room with a reclining chair for me and a rather uncomfortable, straight back chair for my companion. In a backroom, a cauldron of chemotherapy brew is being individually prepared for me while my port is being flushed with saline and blood drawn. The hookup is relatively simple; it resembles an IV, but there is no needle in my arm since it is going straight through a tube into the port in my chest. They always begin with

the drug Ativan. Within seconds, I feel like I am getting drunk and literally pass out. During the next two and a half hours, I sleep—waking up only to go to the bathroom (and pee in a cup, sigh)—and Nurse Kristen administers two of the chemotherapy drugs: Oxilplatin and Leucovorin Calcium. The Oxilplatin is a platinum compound and is the one responsible for neuropathy, which is the tingling sensation in my hands and feet when they get cold. In the worse case scenario, when I've mistakenly touched ice, it feels like hot pokers are penetrating my skin. I try to avoid the cold and keep a pair gloves in my purse and next to the refrigerator. Oxilplatin apparently also adversely impacts my immune system, so I'm more susceptible to colds and fatigue. Leucovorin is an older chemotherapy drug. Both drugs inhibit the growth of the cancer cells themselves.

Surprisingly, after my nice little nap, I wake up pretty alert. (Mind you, I sometimes carry on conversations when I'm getting this injection and yet I cannot remember a thing I say!) Nurse Kristen then attaches my "chemo" box, which I carry in a fanny pack. This is one of the most difficult parts of this process. I hate this box and have my own, not-very-nice nickname for it. It whirs every 20 seconds and feeds me another traditional chemotherapy drug, 5-FU. The box is my constant companion for the next 46 hours; whining incessantly through the music that I use to drown it out to sleep and relegating me to taking baths to protect its unwanted umbilical cord.[16]

The first order of the day on Tuesday is to take three anti-nausea drugs, Emend, Decadron, and a mere $40 pill, Kytril. As an aside, although these drugs are called "anti-nausea drugs," this is a misnomer. A feeling of nauseousness pervades my body for at

[16] It took me until the last treatment before a dear friend loaned me his sound proof earphones that block out the sound of the box. The earphones help immeasurably especially at night because they provide the quiet necessary to sleep.

least seven days following the treatment and all these pills do, as far as I'm concerned, is stop me from throwing up. Along with these drugs, I take my daily battery of Coumadin, a blood thinner so that my body doesn't form a clot because of the port and kill me; Feragon, a super iron booster; and my vitamins of flaxseed, vitamins C and E, and a multi-vitamin. I have found Tuesdays to vary: sometimes I feel okay in the morning and sometimes not. By nighttime or even early afternoon, however, I am on the couch and not feeling at all well. The drug definitely builds in my system and I long for the box to be gone. Generally, I find it necessary to take another anti-nausea drug, Compazine, sometime during the day. It usually holds me over until I go to bed. I then take yet another anti-nausea drug, Ativan, as well as two sleeping pills to combat the Decadron.

Now, please don't get the idea that I'm simply laying around groaning and complaining throughout this process. One of the best things about this regime is that I have someone stay with me for the three days I am getting treatment. This is for many reasons: I can't drive on these drugs; if I throw up, I have to go back to Doc Mary's for more drugs; I probably wouldn't fix myself anything to eat during this time because food simply isn't interesting and if someone else is there I will eat; and finally, the company is a godsend. My family and friends who have stayed with me, plus my very talkative and indomitable kitty Sparky, have served as great distractions from the unpleasantness of the treatment and, despite the pain, I have treasured this time spent together.

By Wednesday, the day is brighter—the box is about to come off! It starts to warn me when it is almost done—BEEP BEEP BEEP! When it is completely empty, it sounds like a police siren. I've managed to avoid anyone driving off the road in surprise at this sound, because I'm usually so excited to get the box off that we get to Doc Mary's well in

advance. The box comes off and one last bag of chemicals is injected into my system, Avastin. This drug is the one that inhibits the formation of the blood vessels necessary to support the cancer cells. Apparently, it has only been on the market for just over a year and is a wonder drug. Undoubtedly to address possible lawsuits, its listed serious side effects include bleeding leading to disability (stroke) or death in lung cancer patients, heart failure, holes in the colon, and kidney damage. I am ignoring these warnings and, to the extent that I have any, I am only giving in to the listed minor side effects of diarrhea, decreased white blood cells, tiredness, and headaches. I leave Doc Mary's on Wednesdays with a lightness in my step. The pernicious nauseousness does not daunt my elation at losing that box.

The side effects of the drugs vary Thursday through Sunday or even Monday. Work serves as a welcome distraction on Thursday and Friday, but tiredness usually sends me grasping the steering wheel to go home mid-afternoon. This week, it felt like I had an electrical current running from head to toe; other weeks, the effects may include a taste of chemicals, a huskiness in my voice, headaches, and, one of the most annoying weekly effects, the inability to drink or eat anything cold for 10 days.

There is also the constant side effect of the bathroom issues. On Thursday through Saturday, the blocked feeling of constipation rises and becomes increasingly uncomfortable. Any advertisements on this subject are dead wrong; there is no such thing as "immediate relief." I eat as many salads as I can leading up to—and through—this period and have learned some interesting new yoga positions for the toilet. But still, each bout yields so little and leaves me physically drained. The days drag on and my only solace is that I'm getting rid of dead cancer cells. Sometime around Sunday or

Monday, the diarrhea hits. I literally hold my breath, praying to escape fire diarrhea for this round. There seems to be no rhyme or reason for when it is fire diarrhea (which feels like acid excretions) or the plain old run-of-the-mill diarrhea. And, when fire diarrhea does hit, there is no escape from pure hell.

Even as I live through this period, I find that my mind quickly dismisses and tries to forget the precise details of discomfort. I don't want to remember. When the effects hit, I focus stubbornly on the fact that tomorrow is a new day and that I'll feel better. While this is definitely not living in the moment and I've never been one to wish my life away, I am willing to make an exception during these times. So, I push on to the Monday through Sunday of the non-treatment week. These weeks are—by comparison—trouble free. Their most poignant characteristic is that the days are so very long. I don't know why this is so. I look back to March 29th and it seems so long ago. And yet, each day just seems to crawl, stumble, and bump by.

Money Matters It won't come as any surprise to you that there is a serious money component to having cancer. It isn't just that there are unexpected, associated expenses that present themselves on a daily basis, it is also confusing to try and sort everything out. Let me start, therefore, with my insurance company, Blue Cross Blue Shield. I now get multiple documents from the company each day (all in different envelopes, wasting paper): "Explanation of Benefits: THIS IS NOT A BILL." Okay, so what is it? I've decided that each of these is simply another chapter in a mystery novel, because nothing adds up. For instance, one sheet stated that the submitted charges were $2,985.00 and the plan allowance was $932.00 and yet I owed the provider $0.00. Truly, how does that math add up? I was amazed when the charge for my surgeon came in at $9,200.00 and I owed $297.53; he was worth every penny and I gladly paid. So too, I happily paid the $100.00 fee of the $20,232.95 hospital bill.

At first, there was a resounding silence from the bill collectors. Then came the flood of bills, $26.22, $16.00, $141.49, $240.00, and $312.00. As more and more bills arrived, I was relieved that they weren't more substantial and that I could keep up without digging into my savings. I must admit to my surprise and absolute disgust, I also got bills from one provider for $.40 and $1.35. These bills felt like an insult and not worth the time to write a check or lick the stamp. I then got hit with the cost of three (or was it four?) chemo treatments for $1,124.05. The size of the bill was rather a shock. Slowly, I recovered. Hey, after all, it wasn't a bad price to pay for life. I half-heartedly tried to calculate how many more sizeable bills I would receive, but it was confusing and disheartening. The only thing that was clear was that I could no longer assume that I could "pay as I go" and would have to move funds from savings.

Before I could act, Blue Cross Blue Shield provided me with yet another surprise. They declared me a catastrophe. Well, okay, that's what I say to make myself smile. Actually, the appropriate medical terminology is that I have met my catastrophic protection maximum of $4,000 and therefore, I am no longer responsible for any deductible, prescription drugs, coinsurance, or co-payment for this calendar year. So, even though I am responsible for the bills that continue to arrive because the costs were incurred before I met this maximum, I am free from any further payments during this calendar year. I congratulated myself on my timing; by getting the diagnosis early in the year, I am hopeful that most of the expenses will all be in this one calendar year. Isn't it great that I've "chosen" the most economical way to have cancer?! Yes, these are the thoughts that amuse me these days… .

There are a myriad of other out-of-pocket expenses associated with cancer. Despite my use of medical terminology ("cranial prosthesis"), Blue Cross Blue Shield did not cover my $1,500 wig. My family, in particular Nesa, has paid for a lot of money in plane tickets and change fees to be with me throughout most of the treatments. When I protest and want to pay, she puts me off by saying that it is "our" cancer and that this isn't all about me! Humbled, this strengthens my resolve and reminds me of how lucky I am to have the family I do.

Surprisingly, the cancer has also attacked the way I think about money. Being single, I have always been concerned to ensure that I have enough money to live a long and full life as a retiree. I am careful about spending money on material and completely frivolous things. Cancer has caused a loosening of the purse strings. For instance, just before going to London, I spent money on clothes that I wouldn't have ordinarily bought.

It felt like I was making a statement about my longevity: I would be around to make use of these things. I have also spent money on pedicures—something I had never done—but my bright red toes make me laugh and laughing is good thing, especially now.

With the skies gray, I will admit that my mind drifted to how quickly all my assets could be liquidated, if necessary. I need to make sure that Nesa, my executor, won't be strapped for cash before my house sells. As quickly as my thoughts drifted down that path, I brushed them away. I am not ready to go there yet and, if that eventuality occurs, I hope Nesa won't mind that I didn't attend to it immediately.

It's Sunday now, the rain has gone and I am back to my stubborn, fighting form against this disease. Thankfully, my good humor has reasserted itself. Importantly, I have another treatment week behind me. I'm looking forward to Labor Day weekend so that I can go to the ocean for a few days, and then on to a glorious fall. Looking back at the last few days and the dip in my spirits, I realize that cancer is as much a part of my life as my shadow: it gets long and pronounced during treatment weeks and then alternatively diminishes during the nontreatment week. I can't escape it, it is attached to every part of my body, including my mind, and it mirrors my movements. I can usually deal with it, but it troubles me the most when, like these past few days, it casts its shadow over my psyche. Luckily, luckily, I have you who call and cause me to laugh, and share the details of your lives with me so that I don't have to concentrate on mine during these times. You remind me of why I'm glad for another day….even if my shadow is with me.

Thanks for listening,

Lindy

Connections

"The best and most beautiful things in the world cannot be seen or even touched.
They must be felt with the heart."
Helen Keller

Hi all—Life is askew, our City soggy and sunk beneath the normally docile Lake Ponchatrain. My brother and I were on the phone continuously in the days leading up to and following Hurricane Katrina; we always are when a hurricane threatens our City. My brother worked for a Cajun tugboat captain on the Mississippi for years. As for me, I went to Tulane for a law degree and, unlike East Lansing and even London where I also studied, I walked away with a love for the City of New Orleans firmly entrenched in my heart. On the first day of school, they taught us how to say both "Two-lane" and "Naw'lins". Classes were cancelled on the Friday of that first week because a hurricane threatened. Bob called to make sure I had the bathtub filled with freshwater, a battery operated radio, and an axe in case I had to go through the roof. My initial puzzlement, followed by disbelieving laughter, did not amuse him! He also cautioned me against going outside if there was standing water, because of the possibility of encountering a water moccasin. That advice got my attention.

Thus began our joint hurricane watch on New Orleans. Living in Pensacola, Florida and having survived two hurricanes in the last 18 months, Bob amazingly predicted the path of Hurricane Katrina, the flooding of New Orleans by Lake Ponchatrain, and the Biloxi gambling boats landing (on) full houses.

If you haven't yet been to New Orleans, it may be difficult to understand how a city can nestle its way into your heart. New Orleans has a way of conquering almost everyone that spends any amount of time there. One of my favorite things to do was to wander through the French Quarter on weekend mornings with my best friend from law school Shar, listening to the jazz as it wafted out from various holes in the wall and hung in the air. We would eventually succumb to a lazy day, our resolve to go to the library and study evaporating as we sat at an outdoor cafe drinking a cold beer and listening to the music.

As much as jazz is an integral part of the City, so too is the Mississippi. The river winds through town in such a manner that it appears that ships are driving down a road just a few blocks away. My daily run was through beautiful Audubon Park, with its majestic live oaks dripping with Spanish moss. I ended each run on the levy so that I could catch a glimpse of any passing tug or ship. Despite the heat and humidity, I spent hours riding my bike on roads that stretched endlessly through bayou country. Out of nowhere, I would come upon an ol' country store where inevitably a few locals would be sitting outside, not moving very fast and talking slower still. It's just a different life, with a different and alluring rhythm.

Our other favorite outing was to go across the bridge to Jean Lafitte National Park. The Park had boardwalks built alongside the bayous and, every spring, we would see baby alligators and unfortunately a lot of writhing black snakes. Shudder. Unbelievably, on the way back from the Park, there was a drive-through daiquiri shop. Yes, just as much as jazz and the Mississippi are pillars of New Orleans, so too are alcohol and food. I have never before—or since—lived in a place where it is frowned

upon to leave any amount of alcohol in your glass or bottle; plastic "go" cups are provided for you to take it with you out the door and on to the street. We had our favorite haunts: the Maple Leaf which had Cajun music playing on Thursdays, Cooter's for its pool tables and oyster bar, the Boot just because it was near school, the Napoleon House in the Quarter, and others whose names have fled my memory but which I could lead you to tomorrow…that is, if Hurricane Katrina left them standing.

As for the food, there were simply too many options, even for budget-constrained law students. We often went to Frankie and Johnny's, where the juke box rocks and trays of fresh "mud dogs" (crawfish), shrimp, crabs, and oysters are standard fair. I recently went back there; however, now that I have given up eating my "clients" (*i.e.*, ocean critters), it was challenging to find something to eat. Nevertheless, the next time I'm in New Orleans, I'll definitely visit this old haunt.

To me, there is no question whether the City will survive Katrina. It is simply inconceivable that it would be moved somewhere else. It is too hard to move a legend, a place about which songs are sung, and which reeks with history. Honestly, there are times when it feels like pirate ghosts are whispering at your elbow. The people too won't go. They are a stubborn and hardy lot and, while they are undoubtedly traumatized and face great challenges, most of them won't relocate permanently away from their City. As I said, New Orleans wiggles its way into your heart and blood and it will take a lot more than Hurricane Katrina to wash all of this away.

Bob and I started watching the Hurricane when it swirled its way through Miami. When it was tagged as a mere level one hurricane, we knew that this was only temporary and that it would soon be a storm with which to be reckoned. Now please don't get the

idea that I am in any way being a Monday morning quarterback, I'm not even sure what a quarterback does! We knew this only because of the very name of this Hurricane. You see, my Montana sister is also Katrina and she herself is a force with which to be reckoned. Similar to this storm, she is at times wild and unpredictable, has amazing energy, and definitely leaves an impact in her wake. That is, however, where the similarities end. Although the doors are locked on a few memories in my mind's museum where she drove me to distraction, she is a pivotal point in our family. She provides us with an endless source of "Trina" stories, and she is fiercely loyal to those she loves. Her laughter is infectious, she has the gift of gab, and she makes each person she meets feel incredibly special. I have leaned heavily on her during my chemo weeks. Her calls draw me to Montana as she describes the pileated woodpeckers on her feeder, the mountains, and her latest golfing or quilting exploits. I actually feel as if I'm sitting in her living room as she talks simultaneously (and at times on different subjects) to me, Maggie the dog, the kids, and her husband. With the busy details of her life, she leads my mind away from focusing on the whirring box and the constant pit of nausea.

Trina, as usual, laughing and having a great time!

As we watched the news roll in on the devastation, Bob and I talked about mobilizing. He was ready to take his mighty "Sea Ark" (his beloved fishing boat) over to rescue people, but he couldn't find anyone to call to tell him where to go or what to do if he managed to get near the area. I cursed this disease because, as much as I want to go south, I am tied here. So, not being able to go ourselves, we sent our emissary, Mom. Mom has been a Red Cross volunteer for over 50 years and has been sent out in the aftermath of several hurricanes. After transferring through Houston, she was sent to the Cajun Dome in Lafayette, Louisiana.

The tales from the front are typical of Mom. Initially, there were over 5,000 people in the Cajun Dome and now they have leveled off at about 2,000. It sounds as if she walks miles each day, making laps around the arena. She has managed to reconnect several families, help others get clothes and a home to stay in, find a doctor for a woman in labor, and provide supplies to medical staff when needed. At other times, she has been

preparing trays of food, collecting laundry, or doing any other task—no matter how menial—that looks like it needs to be done. She befriended one Spanish speaking couple and, since she doesn't speak Spanish, they communicated only through smiles, hugs, and gestures. Before they were transferred to Houston, they sought out Mom to give her a hug and tell her they loved her. It was an example of the true payment for volunteers.

Dad and I once tried to figure out why it is that people seem to gravitate toward Mom, especially in a crisis situation. It could be her firm handshake or even firmer, and readily given, hugs. There is also a forthright Midwestern honesty about her that is as evident as a bright winter overcoat. Even when the news is bad, Mom does not engage in doling out platitudes about how everything is going to be all right, because it just might not be. We finally decided that the true draw is simply that she operates from a sure sense of self and that things, good or bad, are the way they are supposed to be. Life just isn't that complicated for Mom. She listens, sheds big crocodile tears with people, and provides that hug that doesn't change the facts but somehow makes all the difference in the world. It has been hard for me to have her gone and generally out of touch. Yet, I know how to get through my chemo weeks, and it is much more important for her to be where she is. She and Dad are, however, coming to see me through the final round—then undoubtedly, Mom will head back down to Mississippi or wherever the Red Cross needs her.

Mom: ready to go whenever Red Cross calls her!

Averting Your Gaze Our trip to Assateague/Chincoteague over Labor Day was fantastic. When I saw the ocean for the first time, the five-year kid—which is still very much alive inside me—whooped with glee and I wanted to run around in circles in the sand until I fell down. Instead, I dug my toes into the sand, sucked in deep breaths of ocean air, and didn't wipe the smile off my face for three days. The beaches were a colorful, crowded array of beach umbrellas, people playing frisbee, kids (and grownups) building sand castles, and fishermen. Several kites bobbed and weaved over our heads.

I generally avoid this area in the summer and especially on a holiday weekend. I visit only when the beach is deserted as far as the eye can see and it is only the shorebirds and me darting away from the crashing waves. Now, crowded or not, I simply didn't care; a feeling of peace blew off the ocean and through my soul. To make the picture absolutely perfect, a few minutes after we staked our claim to a small area of beach, we spotted dolphins playing just offshore. Life was perfect.

There was one thing that became embedded in my thoughts over the past two weeks and is the subject of the remainder of this email. At the point where the boardwalk ends in the sand, there was a man in a wheelchair looking out at the scene before him. I half-smiled generally in his direction and then quickly walked off down the beach. I proceeded to have an argument with myself about the incident. Why didn't I speak to him? Couldn't I have at least said hello? Then the other half of my brain argued back, you wouldn't have said hello to a person who wasn't in a wheelchair and maybe it would have annoyed him to have perfect strangers constantly noticing him. Why did I feel it necessary to speak? Alternatively, with my "disability" or "physical challenge," I felt a certain kinship with him, so why shouldn't I speak? Then again, other than hello, what would I have said?

Why is it—or is it just me—that people have trouble knowing what to say when someone obviously has a health issue? Of course, the situation in which you encounter such a person may differ and dictate the answer to this question. But then again, what happens if you are working with a woman who suddenly goes bald? Do you simply ignore the obvious so that you don't invade her privacy or do you say something? If you work with someone who uses a cane or is in a wheelchair, would you ever ask why? Or, do you just ignore it and let them bring it up if they want to do so? Alternatively, if someone told you that they have a serious health issue, what would you say?

I have, unfortunately, been on both sides of these questions. Years ago, there was a woman who worked on my floor and we used to greet each other as we passed in the hall. One day, I complimented her on her hair. After about five expressions fled across her face in a split second, she shyly smiled and told me that it was a wig. Initially, I was

embarrassed and didn't know how to respond. Stuttering and feeling like I had to extract my foot from my mouth, I reiterated that it was pretty. And then I took the plunge and stumblingly asked her why she was wearing a wig. I can't remember now what her disease was, but she eventually ended up in a wheelchair. While some may not want to be singled out for any special treatment, I did not treat her the same after I found out about her health issue. I took more time to stop and talk with her, give her encouragement, and try to get her to laugh. I realized just the other day that I hadn't seen her for some time and I am concerned. Unfortunately, we were just hallway buddies and I don't know her name or where she works. I had never asked… .

I now know how people respond when you tell them that you have a life-threatening disease. The responses have been varied. Some, as I have said in previous emails, don't respond at all or hurry to get away from the subject as quickly as possible. Others swing into the, "I'm-going-to-help-you-fix-this" mode; which, while I wish this could be true, is simply impossible. Still others are incredibly sympathetic, disbelieving, and pissed off. Then there is, to me, the best response—simply a hug or two.

Another aspect of this issue highlighted my vulnerability and, once again, my selfishness. I am so very blessed with great friends in this life. One of them, Sarah, has been my friend since we were in the cradle. To this day, we giggle, cry, and share our lives with each other. We took different paths in life. She has three wonderful kids and has let me experience vicariously, and at times literally, the ins and outs of what it is like to be a mom. I called her last week to tell her about my visit with Doc Mary. My cancer counts had thankfully come back great and well within the normal blood range. Unfortunately, perhaps in an effort to curb my growing euphoria at seeing the end of the

road for chemo treatments or maybe because her darn lawyers make her do it, Doc Mary informed me that since I have the most serious stage of colon cancer, there is a significant risk of it returning. I delivered this news to Sarah and then, because I still haven't processed exactly how I feel about it, I went on talking. I hadn't noticed that she didn't say anything in response—she was too distraught by the news.

A few days later, it occurred to me that I hadn't ever thought about my cancer from Sarah's perspective. Even though my cancer has been a backdrop for our lives over the past several months, I haven't let her say much to me about it. As a weak defense of my actions, in part, it may be because I never stop to think about what I may mean to others' lives and what it would mean to them if I were gone. To do so seems egocentric and, quite frankly, the thought never crossed my mind.

I have slowly realized that there may be a very telling reason why my mind never traveled down that path and it applies to Sarah, my family, and, well, all of you. Not one of you has broken down and had a good cry in front of me. I have therefore been spared dealing with your feelings and thus in a way, with mine. While I have had a few "mini" crying sessions, I have never completely lost it and really cried about this situation. Crying won't change the facts. I will admit, especially this week when I've been sideswiped by more than a few of these "mini" crying sessions, I am afraid to let go and have that cry. It must wait at least until I get through these next two sessions. So, I owe all of you another profound thank you for not forcing me to confront this issue over the past several months. My apologies for my selfishness and not being there for you.

So, as I was thinking about my ineptness at knowing what to say when faced with someone with an obvious health issue, it occurred to me that in general most people stay

—and are comfortable with staying—isolated. I work on the seventh floor of the Department of Commerce and there is only a small NOAA contingent there; the other offices are such things as the Economic Development Agency and the International Trade Administration. When walking down the hall—even when there are only two people around—people avert their gaze or furrow their brows as if in deep thought and do not speak. Why is that? Admittedly, if you stop for an in-depth conversation with every person you encounter, it would be time-consuming and, at least for me, draining. And yet, why can't people simply acknowledge each other with a simple hello? Are we afraid that people may think we are weird if we do so or is it a concern that someone will stop us to talk and we don't have time for it? Are we all in that much of a hurry that we can't even say hello? What if someone really does need to talk and all they are greeted with everyday, day in and day out, are people rushing past?

One of my favorite sayings is, if a person doesn't have a smile give them one of yours. By and large, however, this doesn't seem to happen. In fact, I was amazed when I was looking for a friend of mine on the 10th floor in NOAA's Building III. No one on that floor seemed to know one another, let alone the names of the other offices co-located on that floor! I was so surprised and remarked to my friend that they need to have a floor party.

There are, of course, shining examples of people that are able to reach out and connect with others. Sarah is one of them. She remarked to me at one point that she hates it when people sit down next to you on an airplane and immediately put on their headphones or pointedly don't even slightly acknowledge the person sitting in the next seat. Gulp, guilty as charged. Her remark changed my behavior; I now exchange simple

pleasantries before disappearing into my book. Another example is a wonderful man, Tony, who I met in the seventh floor hallways. He always gives everyone a big smile and hello. Our "hellos" eventually led to talking and I am now delighted to call him my friend. The other person is my pool buddy, Sydney. If I can swim, I now do so in the afternoon instead of the morning. I always look around, expecting to hear her cheery hello ring out. With all these thoughts circling in my head, I got on an elevator of about 10 people this week and greeted them with a cheerful "good morning!" No one responded, but it didn't matter. It made me smile and made my day brighter.

Effects With the Labor Day holiday, I received my chemo on Tuesday and Thursday, and thus it seemed that the effects were much more prolonged than usual. Unfortunately, this meant that I had very little sleep the night before my small office put on its first international law training workshop for almost 100 people. Lucky for me, I decided long ago to like public speaking and I operated on pure adrenalin.

For the first time, the ends of my fingers and a few of my toes felt numb for a long time after the treatment. It felt awkward to write. Needless to say, this rather freaked me out. One of Nesa's friends had this happen to her during her colon cancer treatment and they stopped giving her one of the drugs. I am so close to being done and I do not want them to stop anything. Doc Mary relieved me of my worries. They are going to add calcium and magnesium to my brew to address the problem.

Finally, I will admit to being more tired in general and tired of this regime in particular! After talking to my family members most nights, I find it increasingly difficult to pick up the phone and talk to others at the end of the day. Notwithstanding all

of this and despite Doc Mary attempting to rain on my parade with her news, I remain ebullient that I have only TWO more treatments to go. The end *is* in sight.

Thanks for sticking with me and, as always, thanks for listening,

Lindy

Tell Me Why

"I wonder how deeper the ocean would be without sponges?"
Anonymous

Hi all—I have become a character in Winnie the Pooh. Just as Tigger bounces around joyously, at the beginning of my chemo treatments, I too did the same. You will remember, in fact, that I divided the weeks between those in which I had cancer (chemo weeks) and those in which I did not have it and would joyously bounce through the week, because I felt so good. This unfortunately is no longer the case. Tigger's joyous bounce is now restricted to my spirit alone as my body faces a new onslaught of demons from the treatment. During and after the last treatment, I sometimes fought to put one foot in front of the other. Always one to be strong and busy doing physical activities, I am learning a whole new level of patience with myself and acceptance of help from others. My spirit, while it too has taken a beating, is strong. I can barely keep the smile off my face as I deal with the after effects of the drugs: I can live through anything since I know that this is the *last* time!

Life Isn't Fair Almost one year ago, I made a pact with the universe…or so I thought. I bargained that if my nephew Zack could be made well again and his brain tumor disappear, that I would take on any awful disease that the universe wanted to give me. As his health has dipped lower and lower and I deal with this dreaded disease, I have been truly upset that this bargain didn't work. This attitude, I know, will get me—and more importantly him—nowhere. I have thus gradually come to realize that I have to heal and keep delivering good news on my health for both of us. My recovery gives my entire family strength, especially my brother and sister-in-law, who continue to face the

uncertainties of their son's health. Each of my family members have undoubtedly taken their private moments to break down; however, to each other, we remain focused on the positive even while we are awash in worry.

We have been on an emotional roller coaster especially over the past month. Zack himself must feel like he is living a nightmare. All he wanted to do this fall is become a Seminole at Florida State University (FSU). When the brain tumor started to grow again, he had to watch his buddies go off to school while he stayed home. Undaunted, he signed up for four classes at Pensacola Junior College for the fall semester only after ensuring that the credits could be transferred to FSU. As the workload of the classes grew, Zack couldn't keep up. School and studying, which had always come so easily for him, became hard. He had to drop first two, then the other two, classes. I can't even imagine how he must feel. He can't surf, he can't drive, his life is going nowhere fast, and his body keeps doing things that leaves us all bemused and upset. This week, things grew increasing dim. Some of his bodily functions began to fail and he was flown from Pensacola to the Children's Hospital in Birmingham, Alabama. We simply sit and wait for news.

It is impossible to write about this without tears of anger and frustration. Two new "blooms" grew on the tumor. There was a flurry of hope when his Birmingham doctor thought that it might be Lyme's disease; it wasn't. Although they have apparently exhausted the possibility that the tumor might be cancerous, they gave him a low dose of chemo to see if it would kill it. They also loaded him up with steroids and other drugs in addition to those he is already taking to avoid seizures and sent him home. Instead of getting better, he went downhill fast. His right leg and right hand became impaired,

words became increasingly elusive, and there were times when he didn't recognize his parents. My brother, beside himself, tried to reach the doctor. All he got was "please leave your message after the tone and we will get back to you…" No one did. The next day he managed to talk to the doctor's nurse, who had the audacity to tell him that the steroid Zack was taking (the same one I took) may make him "whiney".

On the third day, my brother demanded to talk to the doctor. He finally got their attention. They began to explore a one in a million chance that Zack has Rasmussen's encephalitis. This possibility was discarded when a MRI revealed that a second tumor has grown on the top of his brain. The doctors are now exploring something called germinoma, which is treatable by the same family of chemo drugs I was given. A biopsy is scheduled for today; we are all holding our breath. If the doctors are right this time, then even though Zack may face some unpleasant side effects, at least we will know what it is and how to treat it. So, we will once again wait, pray, meditate, and, if we can, tell Bob some stupid story to take his mind off this situation, if even for a second, and make him laugh.

Insult to Injury I thought I'd experienced all the side effects that I was going to have with the chemo: the constipation, fire diarrhea, husky voice, tingling in my fingers from the cold, not being able to drink anything cold for 10 days, and the ever present nausea. The past two treatments, however, provided a whole new level of discovery. With the taste of chemicals constantly on my tongue, the most painful—and somewhat embarrassing, although I don't know particularly why—were the development of large, multiple mouth sores. At first, I failed to connect them to a side effect of the chemo. It was only after being jolted awake by sharp pains from the mouth sores and their failure to

go away that I finally, and literally, called uncle…and Doc Mary's office. The nurses weren't surprised at all and prescribed bright orange mouthwash, which tasted like bad, runny frosting. It had the most unpleasant side effect of numbing my mouth so that I felt like I was drooling.

There are other little reminders that something is amiss. I have a constant bloody nose. As a disincentive to crying, whenever tears threaten, the back of my eyeballs hurt. Certain foods startle me by causing the ends of my jaw bones to ache. On the extremely bright side, I actually had enough hair to get it cut. My hairdresser too noticed a difference in the very cellular structure of my hair. Funny, although intellectually I know that the chemo is supposed to be working on my cells so that they start producing normally, I had never focused on the degree to which my entire body would be affected.

Unfortunately, not all of the side effects have been limited to my head. The numbness in my feet and hands continue, although it was somewhat less because of the addition of calcium and magnesium to my mix of drugs. During this period, however, there has been a new sensation in my feet wherein my feet pulsate with what seems like a light electric shock, sometimes as often as every 20 seconds. I don't know whether it is related, but I have also become less graceful than usual! After going to the Calvert County Fair with my wonderful little friend, Mateo, and his Mommy Donna, my folks and I went on a hike out to Calvert Cliffs. It was a longer hike than I thought and stupidly, I had on my clogs. As I began to tire, I tripped nearly a dozen times and eventually fell flat twice. This led Doc Mary to question whether to give me my last treatment, but I stubbornly stayed in the chair and insisted that it was just my clumsiness and not that my feet were going numb. While I would like to credit my attitude with her

decision to proceed, it was probably the fact that Nurse Kristen took her one of Mom's brownies!

My hands are the most problematic area after the last treatment. There is varying degrees of numbness which makes it hard to do things that require fine motor skills. My skin also looks like I've been swimming for several hours and is loose fitting. It is difficult to keep my hands warm, especially when the cold radiates out from bones that feel as if they are made of cold steel. Finally, as perhaps a parting good bye, my "bathroom issues" continued and wracking pain kept me up for an entire night. I just wanly smiled as I chanted silently….the last time, the last time, the last time.

The Nagging Question As I finish my treatments, I have once again began to question why this disease attacked my cells and, much more importantly, whether there is anything I can do to thwart its reoccurrence. Is it the chemicals in the food, the pollution in the environment, stress, or genetics? Although being a vegetarian is supposed to reduce the risk of colon cancer, it didn't make a difference in my case. I will, however, admit that I have not been fastidious about eating only organic foods. While I used to eat very little sweets, I have now loosened that rule to one that if something is made with love (usually by Mom, Nesa, or Trina-pie), it's okay. I also used to stay away from truly good cheeses since my good and bad cholesterol levels were elevated; now, I think moderation will replace abstinence. I will continue to follow the "Lacas Diet" of fresh fruit every morning and try to eat fresh veggies as much as I can.

Since chemo began, I have given my system, and in particular my liver, a complete break from alcohol.[17] Thinking back, I drank on social occasions and therefore

[17] Doc Mary did not require that I give up alcohol completely. However, I couldn't keep track of the days when it was okay to drink it and when it wasn't: was it okay four days after a treatment and up until two days before one? Frankly, I simply thought that my system would operate better and at the peak efficiency necessary to fight the cancer without it.

cannot see how this amount of alcohol would have resulted in such havoc in my system. So, should I cut out everything that is not absolutely necessary for my body to function or simply moderate and enjoy life? I have been known to be very rigid in my adherence to my principles (especially when it comes to the protection of the oceans), but without more certainty that completely curtailing my eating and drinking habits will resolve this problem, I honestly can't see myself doing it. I will generally follow the lessons I've learned over the last few months, but life must also be enjoyed.

So perhaps the cancer was caused by the places where I've lived. I have, after all, lived in some of the world's biggest cities: San Diego, New York, Washington D.C., London, and Paris. Could it have been the pollution in one of these places or has there been a cumulative effect? There were five us who worked in the Judge's chambers in San Diego; I lost track of two of them. Of the remaining three, my Judge died last fall of ovarian cancer, my dear friend Susan is battling with Stage III breast cancer, and here I am with Stage IV colon cancer. Was there something in the building at 940 Front Street? How would we ever know?

In New York, people at my law firm used to wear dark colors, because of the pollution and dry cleaning costs. I never did and many partners used to smile and shake their heads at my peace earrings and colorful paisley pants. When I moved to London, I ran in various parks. I started to question whether running was good for my health as I coughed up black junk throughout the rest of the day. We also watched year after year, from the cafeteria at the International Maritime Organization, as they blasted off the black clouds caused by pollution from Big Ben and the Houses of Parliament. The stark

difference between the clean and dirty parts always made me wonder how much dirt my lungs were being forced to handle.

Undoubtedly, the two healthiest places I've lived were Hartland, Michigan, where I grew up and Moose Wyoming, where I spent each summer during college and before leaving to study for my master's degree. And yet, could there have been environmental factors even in these two places that contributed to my condition now? In Hartland, we spent as much time outside as we could, running through the cornfields, riding our bikes down Rattlesnake Lane, playing in the woods, and catching pollywogs. The only time I ever remember feeling threatened was when we were way back in the fields on our bikes and a plane was circling to spray the fields with pesticides. Mom hurriedly drove down to get us and my small bike got put in the truck while the rest of the kids rode home like the wind.

Moose is an idyllic place located just inside Grand Teton National Park. I spent six summers there, hiking and backpacking in the mountains and working for the National Park's maintenance division. At work, we spent a lot of time doing such things as painting things that didn't move (or even that did move, including a tourist who got in the way of my spray brush), spraying to keep bats out of buildings, and working with various cleaning agents and fiberglass. Notwithstanding the questions that now arise in my mind, I loved living in these two places and it's just too hard to believe that living there caused anything bad to happen to me.

So how do you choose the place where you live? Should fears of getting cancer weigh into this decision? For me, this decision of where to live has always been easy because it has been based on the location of the school or job and the proximity of family

and friends. For others of you, it could be because of a spouse's job, choosing the country over the city or vice versa, or, in the case of one dear friend, it is the ease of leaving the country to fly to Turkey. Our priorities in life shift over time and, when things such as the commute or the burgeoning number of people begin to wear on us, we get restless and start questioning one of the most basic parameters of our lives. As this happens, other places seem to lack all problems that plague us in our current location and moving seems to be the answer to everything in life that is bothering us. Unfortunately—or perhaps fortunately—it is never that easy to extract ourselves from the cobwebs of our daily lives. We weave patterns and routines that are hard to break and it takes a lot of energy to overcome the daily inertia to find a new job and a new place to live. Moreover, there is also the issue of moving away from the community of friends that we have gathered and who provide us with that all important support for the soul.

Darlene and I sharing a laugh, even when things were tough.

It is probably rare that someone moves away from a place because of a fear of getting a disease. I myself have no plans to move because I won't live my life grounded in the negativity of fear and running away from a mere possibility. Also, I have come to love living in the Washington area. Years ago, I went through periods of being dissatisfied with living here and dreamed of moving somewhere closer to nature. At one point, I decided that it was time simply to be satisfied being where I am right now. This decision has enabled me to enjoy the area so much more fully: there are wonderful places to kayak and bike, I have a favorite camping spot near the ocean, there are beautiful mountains for hiking nearby, and I have discovered that there is a wonderful parallel world that exists here that focuses on meditation, alternative healing methods, and yoga. Even more importantly, I have an amazing "family of friends" in this area and, for this reason alone, I cannot imagine pulling up stakes.

Don't get me wrong—I still would love to live in the mountains or near the ocean. For now, however, I am satisfied that there are three airports serving the area and I can get to any place relatively easily. I also know that when the time comes to retire, I may once again face the question of where to live. Then again, I also know that the issue of airports is going to be key, because I will be spending time in New Zealand with my dear Roby, in London with my "adopted sister" Roubs, in Montreal with Monique and Peter, and in Rhode Island with Shar and Tommy, as well as visiting many others of you who are not in the Washington area (surprise!).

Perhaps stress has been a contributing or controlling factor in causing my cancer. Although we all know that stress is bad for our health, its far reaching effects—especially

for certain susceptible people—are far from known. My job in New York City was, without a doubt, stressful. I watched the sun come up over the Statue of Liberty more times than I care to admit and there was always some type of deadline pending. Moreover, my law firm of Cleary, Gottlieb has a culture of demanding perfection and, already prone to striving for such a goal, I succumbed to the pressure of trying to meet these expectations. To take a break, I signed up for Cleary's three month pro bono program, where attorneys help people who are facing eviction. To my surprise, this job was even more stressful than my normal job, because the only stop gap between these people being on the streets and having a bed to sleep in was me. My dreams (nightmares) were filled with chasing after people and filling my apartment with all of the clients whom I had failed!

Stress also occurs even when you love your job. I am one of those lucky people who have long known exactly what I wanted to do, although I will admit to taking a circuitous route getting here. My Dad was the one who gave me my first article on the United Nations Law of the Sea Convention in 1979 and my love affair with law of the sea issues continues. In college, I wrote every paper for my international relations degree on some aspect of the Convention or ocean policy. I even wrote my senior thesis for my philosophy degree on how John Rawls' Theory of Justice could be applied to the distribution of wealth from deep seabed mining. Looking back, my professor probably thought I was nuts! I was also lucky enough to find a master's of science program that exposed me to many if not most of the issues that our office deals with today. I have always joked that I was born with the resume for my current job in my hands.

In the midst of doing what I love, there is still stress: stress associated with concerns that I'm not doing enough to accomplish NOAA's mission of protecting the ocean and its resources, stress from those "occasional" (smile) interagency disagreements, stress because there seems to be a never ending demand on my time and yet only so many hours in the day to get everything done. None of these stressors in and of themselves is unbearable and I still wake up, looking forward to the day and happy to go to work. Having faced off against cancer, I now must look at how I handle all of the stress factors in my life. My mind has wandered through—and rejected—the question of whether this disease is the way that the universe is trying to tell me to move on in my life and do something else for my life's work. Alternatively, perhaps it is just that I have to stop taking issues home with me and taking things personally. It is hard, of course, when one is caught up in the quagmire of an issue to see beyond it.

For me, setting firm boundaries on the things that cause stress is going to be difficult but necessary. These boundaries are important to ensure that the job is only one part of my life and doesn't overwhelm all the other critical elements. Over the past few years, as I have moved more into the meditation and yoga worlds, I thought I had achieved a good balance in my life. Now, however, I believe that they—and getting outside as much as possible—need to be even more fully integrated into my life. As for meditation and yoga, they must become like teeth brushing: I cannot leave the house without brushing my teeth and I certainly shouldn't leave the house without meditating and doing yoga! Undoubtedly, given my past track record with work, I will need to be reminded of these words repeatedly by my family and friends. Not to be melodramatic,

but since I don't have any clue as to what caused my cells to go haywire, effectively addressing stress may be a matter of life(style) and death.

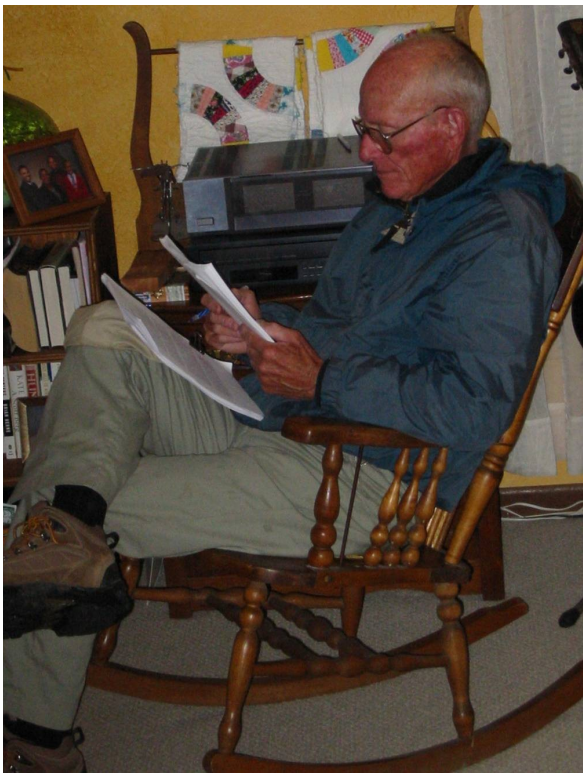
There are, of course, many other things that could have caused the cancer. At this point, with so many foods and things being tagged as carcinogenic as well as those that we haven't figured out might cause cancer, I am forced to stay in the realm of the unknown. You will recall that the doctor at Sloan Kettering did mention that genetic tests might reveal something. I haven't pursued this avenue yet; I'm just not ready to be poked with more needles. I will probably get the tests done, just to satisfy my curiosity and, even more importantly, if it does turn out to be genetic, perhaps gather some information that could help safeguard my precious nieces and nephews.[18]

Finally, before leaving this issue of the potential causes of my cancer, I must admit to musing over the question of whether the mind/body connection could have been a contributory cause. When I was very small, not more than five or six years old, I had a very clear premonition that one day I would have cancer. Since I didn't really know what "cancer" was at that time, it didn't bother me. The thought occurred to me as a stated fact, just as much as the fact that the sky is blue. About five years ago, I revisited this fact and decided that because of what I have learned about mind/body connection, I urgently needed to adjust my thinking. I may have come to this realization too late. (If you are shaking your head at this story, join the club!)

[18] After thoroughly researching this issue and talking to people, I have decided against getting this genetic testing. I kept coming back to the question of why. I myself have to get checked often and periodically. Since the tests have not yet been perfected, I do not want them to create a false sense of security for the others in my family and instead am advocating that they engage in a strict precautionary regime of getting colonoscopies at an early age.

Busy Hands My parents have left. They arrived over two weeks ago to see me through my last treatment and paint the outside of my house. My parents are rarely, if ever, without things to do. I often marvel at their ability to work so well together; my Dad plots, plans, and ponders while Mom simply digs into projects with a pragmatic perspective. Nesa and I often dissolve in giggles as Dad finishes his list of projects with great satisfaction only to find that Mom has discovered just a "few" more projects for him. Dad is simply amazing. He taught himself plumbing, carpentry, how to fix vehicles, welding, and every other practical skill. When the work is done, he finishes the day by working the crossword puzzle or reading. There is always something to talk about with him. Our conversations are lively and range from politics to books to my job to traveling. Always willing to learn, he was the only one who read every draft of my book on *Coastal State Regulation of International Shipping* before it was published (even I got sick of re-reading it!).

Dad stayed a few days after Mom departed to be with my brother, to finish off a few projects that make my life easier. As I drive up to my house with its new overcoat, and look around at the things we did in my yard and in the house, I marvel at my parents' energy. This genetic trait is one I am glad to have inherited. I too am going to be as productive and energetic as them when I am 73!



Dad always supports me in any way he can with my projects:
This time he is editing this book!

Many of you called to celebrate with me that I'd survived my last treatment. Thank you for remembering. I must admit, because of the toll that the drugs are still taking on my body, I'm not yet in the celebrating frame of mind. The real celebration for me will start after November 4th. On November 2nd, I once again get shot full of radioactive dye in order to get a PET scan to see if there are any tumors growing. On the 4th, I have an appointment with Doc to hear the results. The bloodsuckers will undoubtedly take more blood for tests and I will start the once a month flushing of my port. Although I am typing this through a fogbank of tiredness with hands that hurt and feet that periodically pulsate, I have no doubt that Doc will declare me cancer-free. My body always responds well to treatments and this time will be no different. So, don't be surprised on November 4th if you hear a shout of glee that will be heard around the world!

As always, thanks for listening,

Lindy

Awaiting Normalcy

"Life is not measured by the number of breaths you take, but by the moments that take your breath away."

George Carlin

Hi all—YIPPEEEEE!!! I am cancer-free! I know that you all were expecting to hear my yell of joy on Friday; however, my blood results did not come back until this morning. On Friday, I found out that the PET scan—the cellular level test for tumors using radioactive dye—was absolutely clean. I think even my calm, good-natured Doc was excited about that! Today's news further confirms that the aggressive treatment of the past six months thankfully worked. Sigh.

Me being me, I wanted to know exactly which verb to use when describing my condition: was it that I "had" cancer or I "have" cancer and it is in remission? Doc Mary seemed a bit surprised by this question. She said that I *had* cancer, and that there is no evidence of cells that would cause cancerous tumors in my system. Translated (at least by me), that means that I am almost like any of you! I'm NORMAL!!! Well, almost. Doc Mary ignored my protestations and ordered me to get a colonoscopy (bleck), and she will now maintain a watchful, three month vigil on me.

The Art of Being Patient One lesson that cancer has taught me is the art of being patient. I have waited to recover from surgery, for the injection of chemicals, for the wracking side effects of the drugs to pass, for the end of the treatment sessions, for the results of PET scans, and lastly, finally, the blood counts that show that we have beat back the cancer-cells-gone-mad into their normal place within my body. Some of you

may smile and nod your heads sagely when I confess that I probably needed a lesson in patience!

While one can excitedly look forward to such things as Christmas morning and stockings hung with care with a certainty that they will eventually arrive, the kind of waiting I endured was quite different and delivered an unexpected outcome. I was waiting to return to normal and be declared healthy. Unfortunately, while there was always hope that this would happen, there was no certainty about this outcome or even when (or if) it would be achieved. This uncertainty made it difficult if not impossible to look too far ahead into the future. I thus became poignantly aware that any and all plans and dreams of places to visit and things to do were on hold and, what was even more frightening, that they may never occur.

The daily travails of living with cancer for the most part left me with little time to worry about the future. Other than those times when I managed to get through some particularly painful moment by knowing that tomorrow would be a better day, the very sensations occurring in my body left me with no choice but to anchor myself in the moment, living it—with all of its wonder and sometimes painful moments—instead of attempting to parachute ahead into the future. And, since I have been declared healthy today, why would I want to be anywhere other than here? This lesson of living in the present moment is something I've been trying to learn through my yogic studies and yet it took cancer to drive home the point. The universe certainly does have an ironic sense of humor!

In the weeks and days leading up to today, many of you asked me if I felt healthy and whether I felt like I still had cancer. This question made me smile. Since I didn't realize I had cancer stealthily invading my various organs in the first place, I was at a loss to say what was happening inside now. Cancer has been called the silent killer and believe me, this name is quite appropriate! I was left to wait until all the results were in to see if the battering chemo regime worked. Thankfully, it did.

As for my health, Doc Mary warned me that some of the effects from the drugs would last long beyond the last treatment and may even be permanent (my response to this was, no way, this isn't happening in my case!). I think that she was worried that my ebullient spirits would be dampened when the side effects persisted. And persisted they have. The worse effects are in my hands. Various fingers, or parts of my fingers, are still numb and tingling. This makes such things as typing, putting on necklaces, and doing anything that takes fine motor skills difficult. I also drop things more than usual. When my hands get cold, it feels like I can warm them on the outside but the bones remain frozen. Interestingly, while on any given day, the effects will be in different places in my hands, the effects in one hand mirror the effects in the other. It is always the same two or three fingers on both hands that go numb and tingle, or all the tips of the fingers on both hands. My feet too remain affected. The pulsations, like low electric shocks, happen periodically, serving as a constant reminder of the disease and the drugs.

There was another, brand new side effect that caught me completely by surprise. Have you ever seen pictures of a very old elephant, which has not eaten for months and thus resembles a sack of skin and bones, and it seems to exude pain with each step it takes because of the weight bearing down on its bones? Well, other than the fact that I

am definitely not a sack of skin and bones, this is how I have felt for the past two to three weeks. Wherein my dear assistant at work, Alma, could always tell when I was coming into the office because of my fast pattering footfall, I have been moving much more gingerly and slowly—a speed to which I am unaccustomed! Every joint in my body aches. Additionally, at times several large muscles have cramped, reducing me to a limp and finally forcing me to seek out a masseuse to unknot the muscles.

I, of course, thought all of this was just because I was out of shape, not doing enough yoga, doing too much yoga, it was because of my shoes, walking on pavement, sitting too long in a chair, and on and on with possibilities and excuses. Finally, after reading a book about colon cancer where the effect on joints was mentioned (!!), I realized that my discomfort might be connected to the drugs. A call to Doc Mary confirmed it within minutes: it was all part of chemo detox. Lucky me, I'm only 44 years old and yet I now laughingly joke that my body is over 80! It is, again, the worse in my hands. It is almost like having arthritis, with numbness and tingling layered on top of it. In a strange sort of way (and when I can divorce myself from the discomforts of it all), I find it amazing to see how the body reacts and recovers from this onslaught.

Southern Discomfort Many of you ask about my nephew, Zack. Thank you for doing so. It is as if he is sitting on my shoulder every day, he's there with every breath I draw, every step I take. He remains in the Intensive Care Unit in the Children's Hospital of Birmingham in Alabama with his parents standing a constant vigil. His health remains on a roller coaster ride. Three weeks ago, his heart rate dropped precipitously and we thought we were going to lose him. Nesa, who was in the Delhi airport on her way to Bhutan when she received the news, came home immediately. We held our breath and

somehow he slowly regained a little ground. The next week, my brother and sister-in-law kept pointing out that one of his legs was swollen. On the fourth day, Bob finally pitched a fit about it. They discovered a blood clot that was just about ready to come loose in his leg and, if it had, it too could have killed him. He underwent emergency surgery to insert a small mesh in his leg to catch the clot. The following week, Zack had several seizures. This time they found out that the antibiotics they were giving him were interfering with his seizure medications! Sigh.

Through all of these ups and downs, we waited for the lab results to come back on the tissue they took from the second tumor. We were told that they would be back in two to five days and it took almost two weeks. Although the tissue had been sent to John Hopkins and supposedly a top notch lab in California, neither place could identify anything. We also found out yesterday that another young man from Pensacola, 20 years old who used to surf with Zack, has an unidentifiable tumor in his left temporal area. While sympathizing with the family of this young man, it provides hope that some connection between them can be found that will enable us to identify the root cause of Zack's tumors. In the meantime, the doctors are treating Zack with a drug called IVIG, which is made from plasma donations and it helps fight off harmful bacteria, viruses, and other germs. They are shooting in the dark and taking periodic MRIs to determine if the tumors are shrinking. The latest results showed that they have shrunk some; it was definitely cause for celebration.

During the last week, Zack has finally begun to eat a little bit on his own. The first time he ate anything, Bob gave the following summary: Zack had some eggs, a little bit of grits, a small amount of bacon, and a seizure for dessert. Despite the seizure, this

was progress. They now have a physical therapist coming in each day to work with Zack. Since he has been lying in bed for over three weeks, he cannot even hold his head up on his own. We are nowhere near a permanent solution or answer, but take heart in each positive step forward.

No parent should ever have to go through what my brother and sister-in-law are enduring. They sit and watch as their son struggles to live. When they get kicked out of Intensive Care Unit each night, they go to a Motel 8 where there have been parties and loud music by people who don't realize (or care) that others are dealing with a life and death situation. Mom and Nesa have taken turns staying with their other two kids, Nick and Haley. While having family stay with the kids helps ease the strain, Bob and Mel also worry about the effect Zack's situation will have on them. We all wait, pray, meditate, and hope for the time when the entire family can be healthy and back together again.

The Johnson Family

With today's news about my health, there is a lightness in all of our steps, a joy in our voices, and a huge sense of relief. Every day since I received the news, the feeling of being alive just pervades my body. It is impossible to describe the sense of elation. While I know that I will face a test every three months, I am cancer-free for now and life is very sweet indeed.

I could not have walked this path without the support from all of you. You have been there to listen, to talk to, to laugh and commiserate with, and to give me hugs, holds, and love. THANK YOU from the bottom of my heart!!!

As always, thank you for listening, and enjoy this beautiful, beautiful day!

Lindy

The Gifts of Cancer

"If we had no winter, the spring would not be so pleasant:
if we did not sometimes have adversity, prosperity would not be so welcome."
Anne Bradstreet

Hi all! Christmas decorations are popping up all over my neighborhood. Oxford Street in London, where I spent Thanksgiving, was so crowded on Saturday that it was difficult to walk down the street. In the store windows, life size reindeer could be seen hauling sleds brimming with shiny wrapped packages and the latest toys nestled in amongst them. It is that time of year again. I love it. I greet the first snowfall—which I am still waiting for this year—with a giddy sense of excitement. I look forward to decorating my Christmas tree, with its fresh smell of pine, and reliving the memories behind each ornament. There are Christmas cookies to bake while the same five CDs play familiar carols. I search out Christmas plays or music to go to with friends and, of course, there are those wonderful parties that people only seem to have at this time of year. I also eagerly anticipate going home to Michigan. Mom, Dad, Nesa, and I spend Christmas together, playing cards every night, putting a puzzle together in front of the fire, taking long walks through the woods, visiting with the extended family, and Christmas caroling for unsuspecting friends. On Christmas Day, we have a huge bonfire followed by hot chocolate or Dad's homemade eggnog.

The things I love about the holidays do not revolve around gifts. Of course, I—undoubtedly like you—have wonderful childhood memories of filled stockings and beautifully wrapped packages tucked underneath the tree. Most years and especially this

year, I find myself pondering the gift aspect of the holidays. Many of you are likely stressed about what to buy someone, when to go shopping, and the hassle of being in a mall or store when the rest of the world's population arrived five minutes before you did. Why do we do it? Have we simply bought the commercialization of the holidays because of advertisements by stores? Have we allowed them to hijack the wonderful story of Father Christmas? If, however, you were to suggest to your loved ones that you do away with this part of the holidays, you would probably be faced with accusations of being Scrooge or the Grinch. And so on we go, at times grumbling and always getting stressed.

I actually love buying gifts for people and, not meaning to sound sanctimonious, I truly would rather give than receive. It is, however, difficult to find that perfect gift for people, especially these days. Today, if people need or want something throughout the year, they buy it for themselves. Or, if I see something during the year that I think someone would really like, I buy it for them. Excited to see their reaction, I don't wait until the holidays or their birthday, but end up giving it to them immediately. So where does that leave us for holiday gifts? …Chasing after that useful or pretty present that will send the message of love. Alternatively, my sister and others have tried to solve this dilemma by having their friends give money to a charity or dedicating a specific time to do something together.

This year, I must admit that while I have some shopping done, mostly I'm watching the days click past. There are other things on my mind. I have changed and this issue of gift buying no longer causes me as much consternation and worry as in the past. If it gets done, it gets done and if it doesn't, it doesn't. If I don't get gifts for people, I hope that they know that I love them, because I am in their lives, caring about

them, sharing, and making memories with time spent together that last beyond any memory of a specific gift given.

Pure Gifts, Lessons, and Thankfulness Cancer invaded my body and, moving swiftly and silently, almost succeeded in taking my life. Yet in doing so, it left me with many powerful gifts, some of which I am still struggling to come to terms with, integrate into my life, and simply accept. It may seem odd to you to hear that such an insidious disease brings gifts and I am also surprised that this is true. While I would have preferred to be given them without the ravaging side effects of the chemo and the uncertainty that will continually linger about my health, I would not exchange or forego them even with these associated costs.

The gifts fall into three categories: those that are purely and simply gifts, those that have come in the form of lessons, and those things that existed in my life before and the cancer served as a reminder of how lucky I am to have them. It is those things that I think of as pure gifts that have left me the most humbled. The most important of these is the gift of unconditional love that I have been given on a daily basis from all around the world, from people I am close to as well as from people I don't even personally know. This gift of love has been shown in so many varied ways. Packages have shown up, sometimes without a card or label, or from someone quite unexpectedly. Unlike Christmas presents where there are societal norms that dictate when they are to be given and to whom, these arrived simply to lift my spirits and let me know that I am not alone in my struggle. And they have been such perfect gifts, chosen with such care, including beautiful flowers to brighten my day; humorous books, books to take my mind away from the pain, books on yoga and healing, and empty books for me to write in; wonderful

CDs with chants, healing meditations, and other music which I love listening to; personalized hats just in case I lost my hair; a birdfeeder bringing life to my yard; butterfly bushes and other plants and trees; gadgets that create heat to warm my cold hands; boxes of fruit, nuts, and chocolates; a Tulane shirt and a TIGERS! baseball hat; a beautiful painting of a sea turtle; a contribution for the protection of the marine environment when I couldn't do it myself; cookies, spices, and other delectables; and so many other things.

This gift of love was also shown by so many cards, emails, and phone messages. They helped take me out of my own life, especially when it wasn't so fun, and made me smile as I remembered the sender. They gave me something to look forward to, provided a much needed form of encouragement, and strengthened my resolve to beat the disease.

I was also given this tremendous gift in the form of prayers and the sending of energy. Some of you told me that you prayed for my health with your kids at night, even if the kids didn't know me. This still brings tears of gratitude; thank you and give those kids a big hug for me. I was also put on numerous prayer lists in a wide range of religions. Rosemary, Erica, Rudy and Sharon, Sonia and Philip, Cherryl, Cheryl, Mrs. Wank, and others sent me healing energy. I drank it all in and my body used it to heal. There are studies that back up the power of prayer and energy to heal. I believe it and, even if I didn't, just knowing that there are people out there concentrating on my well being provides me with an enormous amount of comfort.

Another gift during this time was being surrounded by my family and my family of friends. My family, about which you have all heard so much now, amazingly became even closer. I have some great memories of them during this time. Mom sending me off

to surgery, laughing so hard that tears were running down my checks, because chocolate melted in her pocket and all over her pants; tucking blankets around me so tightly that I could barely move; and baking up a storm. Dad, upon hearing the news of my cancer, drove straight across the country from Arizona. When he arrived, he simply sat in the chair near me as I lay on the couch so we could talk. He executed a million projects both inside and outside my house that now make my life infinitely easier. Mom and Dad also transformed my backyard into a beautiful, peaceful haven. Nesa, well, she is my rock. She was always here, smoothing out the corners of my crumbling life and making me laugh while doing it. I gave Bob a new nickname during this period, Sunshine. I looked forward to his calls everyday. Here he was, trying to deal with his own son's illness and yet he took the time to check on me and make my day. As for Trina-pie, she simply refused—and still refuses—to let me lapse into worry about myself or Zack. She *is* the guardian of my positive attitude. Then there is my "sobrino" (nephew), Steven, who when released from his duties as a marine, stops by with that big smile of his just to chat and check on me.

My support network

I cannot even begin to relay all the wonderful memories I made with my family of friends: from Monique, Karen, Nanc, and Jacqueline living through a chemo treatment with me, to Bry doing cancer research when I simply couldn't face it, to the ministries of my wonderful acupuncturist Erica. Dar continuously brought over food to feed an entire city (or at least enough for my nephews!). Shar came down from Rhode Island three times and frequently called to check on me, and Cass was a constant who gave up smoking just because I asked. Donna, Roger, and Mateo and Sarah and the kids provided much needed distractions and made me laugh. Bry, Cotton, Janet, and Molly went paddling with me and Roger and Donna and Molly took me to baseball games. Karen, Mike, and Kate cooked a wonderful brunch and ensured that I saw the March of the Penguins. There were also so many others of you who stopped by and yet were wonderful enough to see when I was getting tired and leave. My favorite thing about spending time together was that no one concentrated morbidly on my illness, but shared

stories of what was going on in their lives or the world. In this fractured, busy world, the absence of community is often lamented; however, I know now with certainty that I have a strong and wonderful community, and one which I can lean on heavily in times of trouble. It is truly a gift.

Donna and Mateo, as cute as can be!

I received one of my favorite gifts (and by far the loudest) from my siblings: my kitty, Sparky. As some of you know, she talks constantly and is very insistent. If for some reason I am not up by 5:30-6:00 a.m. for meditation, she wakes me up and then proceeds to the meditation room where she (amazingly) sits quietly for the entire session. In the evenings, she watches out for my health. Around 7:30, she tells me to sit down, stop my busy-ness, and rest. At 9:30-10:00, she meows so insistently that she has driven guests away and me to bed. There have also been times when she has greeted me at the door, with her paw seemingly on her hip, yelling at me because I've been gone too long

or the heat isn't high enough and the house is a bit chilly. Yes, she is a force with which to be reckoned. Her antics provided a much needed source of distraction and laughter. She always seemed to know those times when I felt rough; she would nestle against me, watchful under half closed eyes. Sparks has brought a different dimension to my wandering feet, making me realize how wonderful it is to spend time at home and that I can actually make a commitment to do so. Ah yes, a fundamental change in my life provided by the gift of cancer.

Sparky laying in one of her favorite spots.

Cancer has given me the wonderful gift of new people in my life or a new dimension of friendship with others who were already there. As part of the cancer community, there is a bond. I have discovered new friends who are also facing colon cancer, my favorite being my adopted "Uncle Bill" who is actually Cowboy Nan's Uncle. We have shared stories, our fears and demons, humor, and encouragement. Others have shared the news of their cancer with me, which immediately serves to deepen the sense of

compassion, camaraderie, and friendship between us. The cancer community is truly a community and, even though no one ever wants to be a member, I have found that belonging brings an instantaneous source of connection, support, and love. It leaves me wondering why this sense of community doesn't exist among people in general. Before leaving the discussion of this gift of new people in my life, most surprisingly and in between treatments, I met a wonderful man. Once again, the ironic humor of the universe reveals itself! At a time when I am definitely not at my best, I have been handed an amazing gift.

The last "pure gift" is that of Doc Mary and her staff, in particular Nurses Kristen and Jen, Sandy, Kathy, Maria, Lindsey, and Trisilla. Their caring, laughter, and joyfulness made a bad experience almost enjoyable…well you know what I mean. They greeted me like a trusted friend whenever I came in and rejoiced with me with each piece of good news. When David delivered flowers during one treatment, several of them gathered in my room to get the details about him and our relationship—I felt like I was back in high school or college! Even when Doc delivered bad or cautionary news to remind me of the seriousness of my case and the possibility of the cancer returning, she did so in such a way that I knew I wasn't alone; she and her staff would be there for me, no matter what happened. And they were—and still are—there for me, not just to support me with my own health issues, but also to talk about Zack.

Doc Mary's Head Nurse, Jen, who provided advice to me not just on my situation but also tried to help me understand Zack's situation.

The second category of cancer gifts is the lessons I've learned along the way. Long ago, I learned that while we may all want to be happy and carefree all of the time, it is in times of difficulty that we learn and grow the most. Cancer has been such a growth experience for me. I would like to assert that I've integrated fully all of the lessons that have been presented, but that would be an incredible exaggeration. Even though faced with the possibility of death, I am far from being perfect and filled with goodness. I am still human and make mistakes; I get frustrated and say the wrong things. Accepting my fallibilities and foibles is too another lesson of cancer. I spend less time kicking myself and more time on attempting to integrate the lesson. Above all else, I am persistent and stubborn and simply refuse to believe that I cannot change to adapt new habits and more peaceful ways of living.

Perhaps my favorite lesson is a new appreciation of people. We cannot tell from mere appearances what a person is going through or facing in their personal lives. If someone didn't know I had cancer, they could not tell from my appearance. There were times throughout treatment when people would tell me something and I would not have any recollection of it. Lucky for me, this tendency became a source of amusement, with some of you suggesting that they were not "chemo moments" but were actually "senior moments"! People cut me slack and I very much appreciated it. I now try hard not to be judgmental and more understanding of where people are in their lives. I no longer expect people to keep up with my previously high energy level. This lesson has resulted in less frustration and a greater acceptance of myself and, most importantly, others.

Cancer and chemotherapy have, by their wicked ways, taught me to live in the present moment. They have caused me to slow down. Used to running at full speed, this, of course, has tormented me. I have had to learn to be gentle and forgiving of myself. I have to laugh at my forgetfulness and try not to get frustrated when I drop things or trip repeatedly. My body is constantly speaking to me and, even now as I detox from the chemicals, the sensations and feelings change. As they change, my ability to do things also changes. I have to adapt continuously and strive to do so patiently. I have had to accept that there are things that I cannot do right now, how to accept—and ask for—help from other people (something I have never been good at), and learn to say "no" even when I may really want to do something.

One of the hardest lessons for me is that of letting go. I am used to being busy and accomplishing a tremendous amount in any one day. I have learned that multi-tasking is overrated and, in extolling its virtues, people miss the beauty of being fully

present in one task before moving on to the next. Now, I try to prioritize and, taking deep breaths, let things go. My priorities have had to shift. I have to put my health as the top priority. That includes such things as getting enough sleep, stopping when I'm tired, eating properly, and getting exercise. Yes, you've heard all these things before and so have I. The trick is, especially when there is a work issue to be done or even something fun to do, remembering to make the health items a priority and therefore a lifestyle.

Lastly, I have learned the powerful lesson of distraction. Distractions are supposed to be bad, but like most things that have negative connotations, they have their place. During this journey, I have learned to distract myself when times became particularly hard. By focusing on something else at hand, I could move my mind away from needless worrying or obsessing about something that I could not change or affect.

The last category of cancer gifts is the thankfulness category. Oh yes, there are definite overlaps in these categories and, believe me, I am very thankful for everything I have said above and in particular my family and friends. In addition to these, I am so thankful that many years ago I began the practice of yoga and meditation. They have been invaluable in helping me through this period of my life. Erica's acupuncture too has eased the pain and facilitated my healing. I am also extremely grateful for the way I was raised. We were encouraged to stand up to challenges and look at life as presenting opportunities. My parents exhibit positive attitudes and the ability to find things to laugh at, even when times are tough. These things helped me immeasurably.

Every day since March 29th, I have been extremely thankful that I was generally in great health when the cancer struck; it has helped in weathering this storm. I am also keeping my fingers crossed and am grateful for the fact that, even though I had a

complete hysterectomy, I have not had any issues associated with menopause! I am also thankful for my wonderful house and backyard; they have provided a restful, peaceful, and welcoming haven. Finally, I have found strength in my belief in a higher power and my own spiritual practice. It has helped me find peace when troubled and acceptance that there are just certain things out of my control.

Flying South The weekend after I received the full report on being cancer free, I headed south to see Zack, Bob, and the rest of their family. Zack was still in the Special Care Unit and, at that time, had been in bed for five weeks. Efforts at identifying the tumor had failed again (in fact, wherein before they thought that there were two tumors, they realized that it was one connected, fast growing tumor). His doctor had sent samples to the best pathologist in the country at John Hopkins and, in reporting that he could not identify it, he said that over the past eight months he had seen more unidentifiable brain tumors than in the rest of his career combined. Zack's doctor even posted his treatment and other information about his case on the web, hoping that someone would see it and know something that would help.

They are continuing to treat him with steroids, antibiotics, the drug IVIG, and even chemotherapy. Problematically, some of these drugs stop being effective after awhile or cause other nasty things to happen so he has to be taken off them. His latest MRI, taken just a few days ago, revealed that while the growth on the top of his brain was apparently responding to treatment, the primary tumor is "enhanced." Whatever that means, we know it isn't good.

I felt amazed and simultaneously helpless as I watched my family hover around Zack. My sister-in-law, Melani, rattled off the name of the drugs he is on and watched

any nurse that came near him like a hawk. Tears welled up in my eyes as I watched my brother's big hands (and even bigger thumbs) turn velvety soft as he doggedly and constantly moved Zack's head upright after it slumped to one side, take his limbs and move them through a series of exercises to avoid atrophy, and dress the chemical burn on his foot (caused when he was receiving medication through his feet and his foot cramped). Bob helps change and bathe Zack; he watches the clock and ensures that the medications are given on time; and, although bantering good naturedly with the nurses, his guard is never down as he keeps a watchful eye on them. All the while, Bob keeps up a steady stream of chatter to Zack. He talks to him about football, the weather, and anything else that crosses his mind. Zack's eyes would follow Bob around the room and I often found myself wondering what Zack was thinking.

Walking around the hospital with Bob was a treat. He seemed to know everyone and they him. The ladies in the cafeteria in particular seemed to look forward to his multiple daily visits and, even though they piled his plate with food, they never seemed to notice much of it at the cash register. To Bob, it doesn't matter whether they wear doctors' scrubs or hold a broom, he treats them all the same. That's just his way.

Each day, we hold our breath and pray for improvement. Zack began to eat while I was there. He clumsily held his fork and concentrated hard on getting food on to it and then up to his mouth. We stood by and cheered for him. When he was tired, we would feed him. Nesa usually took over this role. One time after he had finished everything on his plate, she congratulated him and said that eating solid foods was the way to recovery. He looked at her and with great effort said clearly, "I'm trying."

The last day I was there, they actually moved him to the floor and out of the Special Care Unit. Even though this meant breaking in a new set of nurses and that there would be fewer nurses looking after him, we were elated. This meant that he was getting better. My parents arrived for Thanksgiving and prepared a traditional dinner in a vacant conference room on Zack's floor. Mom made enough of her famous pies to feed the family as well as those who had to work. Zack, who has always loved Mom's pies, finished off a piece and then looked at her and said, "thank you."

With Zack getting marginally better, Bob and Melani are now taking turns staying at the hospital and going home to Pensacola, three hours away. They also have their two other kids, Nick and Haley, who are both in school. Bob, being an electrician, doesn't get paid when he doesn't work. While there is always the family safety net, this adds yet another level of stress and worry to their lives. Perhaps most importantly, Bob and Mel need this time to rejuvenate. I spent only two days in the hospital and found it exhausting. Contrary to the expectation that there would be a lot of sitting around and time for reading, there always seems to be something to do whether it is seeing Zack through a meal, doing physical therapy with him, or ensuring that the proper medications are being administered. Moreover, it is draining to keep the continuously upbeat attitude while waiting and watching.

As the days drain slowly into weeks, Bob and Mel rejoice at each sign of normality returning. It is a veritable roller coaster of emotions, with only hope to get them through the low points. Last week, there was talk of sending Zack to a Pensacola hospital and, upon hearing the news, Bob broke down in tears and then was wreathed in smiles. The results of the MRI dashed these hopes and I feared the effect of this news on

Bob and Melani. Characteristically and stoically, they shifted gears quickly. Zack needs to be near his doctor until it is absolutely certain that he is out of danger. And so on we go, praying, meditating, and hoping.

The Tin Man and Sense of Touch There are so many unknowns, uncertainties, and surprises that I have confronted throughout the last eight months. Doc Mary, undoubtedly worried that I would tumble from my exuberance at being done with the treatments to being depressed in the aftermath, warned me that detox could last up to six months or that some of the effects could be permanent. It is an entirely different story hearing something and living it. While of course it makes sense that it would take some time before the drugs leave my body, I just wasn't prepared for these lingering effects. In fact, there were times in between treatments that I felt better than I do now. There is no respite. I wake up in the middle of the night with my hands or feet hurting and am acutely aware of the fact that I had cancer every minute of every day. Countering this of course is the elation I feel on a daily basis that I am cancer free; however, I will admit that my spirits dip at times and I get intensely frustrated by this latest onslaught. The days go by slowly and April—that six month marker—seems a world away.

So, Tigger has been replaced by the Tin Man. My joints appear to be rusted together and, when I get up from sitting, it takes some time before they work properly. It seemed to start first in my hip joints, then move down to my knees and ankles, before migrating up to my shoulders, elbow, and fingers. Right now, while there is still stickiness in all my joints, the most painful is in my left shoulder and always my hands. Instead of using WD-40 (lubricating oil), which I was contemplating (smile), Doc assigned me Glutamine and ibuprofen. I am also trying to drink a lot of water in an

attempt to wash the drugs away. My dear friend Monique also told me about an aurveydic treatment that involves rubbing regular ol' sesame oil on my joints and leaving it on for 10-15 minutes. Although I smell a bit like a Chinese restaurant while I meditate, it has worked wonders to ease the pain in my joints.

The most frustrating effects are in my hands and feet. Especially when I get tired and my feet get cold, I trip repeatedly. My ankles feel like rubber, bending this way and that. Luckily, I haven't fallen flat on my face yet, although it has only been avoided because I was clutching a friendly arm.

The impact on my hands is the most disappointing. Have you ever asked yourself the question, if you had to lose one sense, what one would you *least* like to lose? I, probably like you, always answered this question with my eyes or my hearing and I'm not sure the answer would be any different today. And yet, I never even gave the sense of touch a passing thought. I do now. Everyday. Try this—try to pick up a piece of paper or a pencil, or try to put your earring in or your watch on and imagine that you cannot feel your finger tips. I used to be a fast typist, now—because my perfectionist attitude refuses to let me send things out knowing that there are spelling errors—I frequently have to type and retype, and my little finger has become strong because of repeatedly hitting the delete key. It is hard to describe exactly how it feels, but the best I can do is have you imagine that you have slept on your hand and it has fallen asleep. Ah yes, you know what is to follow, that prickly, needles sensation. I'm stuck in the prickly stage, with a heavy dose of numbness added. I no longer ignore or take for granted this subtle, yet vitally important, sense of touch.

I have returned from London, happy to have accomplished what I went for and to have seen dear friends. This week will be filled with the buzz of holiday preparations, the initial visit to the doctor for the colonoscopy (bleck), getting my port flushed, and meeting with a nutritionist. It is the normal rhythm of life, with its fun and happy moments interspersed with things I would prefer to avoid or ignore. Throughout it all, I rest content in knowing that I have lived through this difficult time, buoyed and supported by all of you. Thank you for enriching my life and, as always, thanks for listening,

Lindy

The Way Forward

"Live life large (whatever that may be for you),
Laugh often and with abandon,
And love unconditionally."
Lindy S. Johnson

Hi all—This email will hopefully be my very last about my cancer journey, *because I am a cancer survivor*. Even now, I find it hard to couple my name with the word "cancer" in the same sentence. Perhaps it is a defense mechanism, but I have always had difficulty remembering bad things that have happened to me and so too it is with many of the events over the last year. The bad memories are becoming hazy and instead I find myself recounting my play dates with baby Mateo, the day my kitty Sparky took over my house and heart, and the great times I spent during this time with family and friends.

Needless to say, ongoing events serve as constant reminders that yes, I actually did live through surgery and the arduous chemo treatments. My hands, feet, and joints are slow to release the drugs and my calendar is peppered with appointments with various doctors, so much so that my truck can almost drive itself to the medical establishment in Fairfax. Also like clockwork with the start of the new year, I began once again to receive a bevy of medical bills. I am not upset by this, however, because as long as I have to pay these bills, it means that I have not reached the $4,000 catastrophic coverage and that is a very good thing!

Integration One of the most difficult issues I had to face in this post-chemo period is how to integrate the fact that I had cancer into my life. It isn't like a broken bone or a cold that you just get over and forget. Last year, cancer necessarily became the

center of my life. So how do I—or even can I—go back to my "normal" life? To my surprise, I found it hard over the holidays not to talk about the cancer. People, of course, wanted to see me and make sure I was okay, but life in Michigan still operated at its normal rhythm and most had not participated in the cataclysmic storm that engulfed 6912 Duke Drive. I chided myself for this feeling, but undoubtedly it was part of processing the events. On the one hand, I didn't want to wear the fact that I had cancer as a badge and assume a victim mentality. After all, what would be the purpose for this? Gaining sympathy or attention? This just isn't me. On the other hand, there are times when I need to talk about the experience and to share it with others. It is equally unhealthy to act like it never occurred. As time has passed, I have relaxed about whether to talk about it or not. I talk about it—or not—depending on the situation and the person. When I need to talk about it, there are many of you who I know I can call and who will understand.

There is one point that has become absolutely clear: I cannot go back to my pre-cancer life. Cancer has carved deep into my very being, my psyche, my physical abilities, and my soul. It is impossible to wipe the slate clean. At times, however, I find myself playing a game, especially as I watch people running on the path by the Potomac River or even as I turn the key in my door on a Friday night and think about the weekend. I try to remember what it felt like before cancer. I used to run carefree, enjoying the outdoors. The weekends were packed full with a million different things. My thought process then was different; my cares centered on work, things that were happening in my family or friends' lives, or planning how to fit even more things into the day. All of this has changed and, funny enough, I don't think this change is necessarily bad. It is just very different.

When I started to think about this post-chemo phase, my thoughts kept returning to the unanswerable questions regarding how and why I contracted this disease in the first place. I realized that this was futile, but it bothered me. How was I supposed to figure out what to do to avoid having the cancer reoccur if I didn't know what caused it in the first place? For someone who likes to chart a course of action—and will stick to it—this uncertainty was unsettling. Eventually, since worrying has no impact on reality, I decided to chart my course based on three principles: good nutrition, stress reduction, and maintaining a positive attitude.

As an overarching philosophy, I had to come to grips with the fact that I absolutely have to make my health my number one priority. I paid lip service to this concept for quite some time; however, how to do this was not clear until one of you mentioned that safeguarding my health had to be my number one job. For some reason, this stopped me in my tracks and made me think about this point in a completely different light. Thinking about it like a job seemed to crystallize and clarify the importance of this undertaking. I also realized that I was resisting putting my health first, because it sounds so self-centered. Quite frankly, this bothered me. Yet, I have come to realize that if I don't keep myself healthy, I may not be here to care for and love the wonderful people I have in my life. So, I now have a new organizing philosophy in life: my health.

Being a vegetarian, I always thought that my nutrition was pretty good. Obviously, something went wrong, so I decided I needed help on this issue. My dear friend Mary Anne led me to a wonderful nutrition counselor, Cheryl Mirabella, who doesn't just say junk food is bad, apples are good, but is helping me look at my eating habits holistically.[19] For instance, I am focusing on how I feel after eating certain foods

[19] For information on Cheryl and her wonderful services, check out: www.livingwholehealth.com.

and what emotions led me to eat them. Ah yes, stress leads to sugar so that I can keep operating at a fast pace! I am reviewing and rethinking my old eating habits. This isn't a diet where certain foods are forbidden, but a process focused on my body and what I need to do and eat to make it operate at peak efficiency. Luckily, I love new projects and learning and so am thoroughly enjoying this new venture.

Stress reduction requires hard choices and a constant vigilance. While in my earlier email, "Tell Me Why?," I identified several stress factors, I once again took a hard look at the major stressors in my life. The most obvious, which I identified earlier and which is probably shared by many of you, is work. For me, stress does not occur at work because I am unhappy about the issues on which I am working or from those with whom I work. On the contrary, my stress arises because there are too many issues I would love to address with people I truly respect and admire. I thus need to be careful not to take on too many things at one time.

Another more complicated stressor for me involves my emotions. In the past, I have tended to take certain world events almost personally and internalize others' problems. I was devastated and depressed after the 2004 election and the subsequent U.S. military operations in Iraq. When a friend or family member has a problem, it upsets me almost as if the problem were mine. I have to keep reminding myself that I can only work to change what I can in the world and leave the rest up to the universe. As for my friends and family, it isn't helpful to them for me to psychologically "take on" their problems. By sharing with me, they are not asking me to do so and moreover, it's impossible and silly to even think that I could or should. Believe me, I didn't realize that I was even doing this. I found out only by participating in an incredibly intensive soul

searching weekend at a yoga retreat. So now, even while I am working on not becoming consumed as I used to, I am trying to remain open, compassionate, and loving to my friends and family as we discuss the issues in our lives.

The other major stressor in my life occurs when I have too many competing demands on my time. No one in my family sits still very well—being active is a family tradition. I have always had an abundance of energy and a capacity to do a tremendous amount of things in any given day. Impulsively, I still build my calendar, packing it full, without thinking. When I share my plans for the next day with those of you who are my guardian angels, I have been greeted with raised eyebrows and even laughter. Grumbling, I cross things off the list and rearrange my day. It is a hard lesson for me to learn that my time each day is finite: I must learn to spend it wisely and choose how to apportion my energy and resources. Hopefully, I will get better at this and even set aside time each day (in addition to my morning meditation) just for being in deliberate stillness.

As a potential tool in stress reduction, I am also reviewing my habits. For instance, and as a rather silly example, if I have always parked in a certain location, I have begun to park somewhere else. By doing this, I want to see if my habits are serving me best or if they need to change. It also has the additional function of keeping me in the present moment…although I will admit that the other day I spaced out on my way back to my truck and my feet simply followed the old habitual path, so I was left standing in the parking lot confused and wondering where my truck was!

My efforts at stress reduction have not all been easy and have led to major life changes. As I told you in an earlier email, my dear friend and boss retired last year. I had

always been on a trajectory of applying for the head of our office and truly never questioned the decision of whether I should apply for the post. Thanks to my cancer journey, I had to stop and rethink it and, after a very, very difficult period, decided to withdraw my application. It was a difficult decision on many levels, including that our society tells us that we are constantly supposed to be moving up the ladder to be successful. With this decision I stepped off that ladder and, contrary to my personality, eschewed taking on additional responsibility. Alternatively, I said "yes" to the life I have, to the job I love, to my "clients" (the program offices, the right whales, the coral reefs, and the marine environment in general), and, most importantly, to myself. Yes, of course, there is stress associated with the fact that I will have a new boss, but I choose to believe that the person who fills this position will be wonderful and that we will get along just fine.[20]

Meditation, acupuncture, and yoga are also essential tools to help me reduce my stress. The most difficult of these has been the yoga. The detoxification from chemo has caused joint pain and certain muscles have become unbelievably tight. Sometimes, after a yoga session, I feel stiffer than when I began, which in moments of despair and remembering the ease of my practice before cancer, I wonder why I am even trying. Yet, the four corners of my yoga mat act like a mirror of my life. There are some poses that used to be so easy that are now incredibly difficult (such as balancing postures), just as there are certain things in my life that are now difficult. I know that with practice, perseverance and, most importantly, acceptance of where I am today, it will eventually get better. There are some poses now that I find myself a bit fearful to try. Interestingly,

[20] Since I initially wrote this, the position has been filled by a wonderful man, Peter (Poppy) Oppenheimer. Not only do I respect and admire his crackerjack intellect, but he has a warm and gentle personality too.

they aren't the headstand or handstand, but those involving stretching the abdomen. There is a bit of pain on the left hand side of my belly. I shy away from anything that creates a twinge, instead of breathing deeply and exploring it. I know from past experience that by breathing into the area and moving slowly with the right attitude, I can let the fear go and my body will take care of itself.

Yoga also teaches that each day is different, some better and some worse. The point is to focus on accepting myself wherever I happen to be that day. And this focus on "self" is key. It does not matter what other people are doing (in their poses or life) or even what they think of how I am doing, the important point is to listen to my body and follow its wisdom. Finally, the practice of yoga constantly reminds me of my fundamental belief that difficult poses (issues) help us to learn and grow, and definitely make us stronger.

As for keeping a positive attitude, this is generally the easiest principle to implement. Lucky for me, it is my nature to be generally upbeat because my parents taught me this from the day I was born. If a situation occurs where I start to falter, I can always count on support from Trina-pie, Nesa, Bob, and Mom and Dad to help me through it. I am leaning on them hard at this very moment. There were some shining moments of hope in my nephew Zack's recovery when he was moved last week from the hospital in Birmingham to one in Pensacola. He was gaining in physical therapy and I even understood some things he said during a phone call. That all changed this weekend. Zack had a massive seizure, during which time they think he had a heart attack and his kidneys failed. We are now hanging by the phone, meditating, hoping, and praying for that elusive miracle.

Face-to-Face There was so much that I didn't know about cancer when I started this journey. On our first visit with Doc Mary, I asked her when I would be declared completely free from the cancer world. After all, I had heard that for some types of cancer that if you survive a certain number of years beyond treatment, your risk was the same as that for everyone else. In her forthright yet comforting way, she shot that hope down by basically telling me that I was a "lifer". That is, I am always going to be at a significant risk of the cancer returning and we will have to keep a watchful eye on things. After I digested this unwanted news for a minute, I asked her if she was ready for at least a 40 year relationship, because I intend to live a very long time!

So, I am about ready to face my first quarterly "report card" this week. Long ago I thought about having to face the question of whether the cancer has returned every three months. One option was to be scared and apprehensive before each visit. In fact, I could choose to be this way for a day, a week, or even longer before each result. I decided that this would be a complete waste of time, and that worrying would get me nowhere.

I will admit that I am not particularly thrilled with the tests that I have had to endure to be ready for this report. For instance, I had to have a colonoscopy just before the holidays (bleck!). Doc Mary, of course, sent me to an absolutely wonderful doc, Doc Adams.[21] We had a great time chatting, during which I laid out all the reasons that I shouldn't have to have a colonoscopy right now (after all I am nowhere near 50 years old yet!). She laughingly told me that I was going to have one anyway. Then there was the CAT scan. I had to drink two quarts of this awful stuff, barium. It is the color of chalk

[21] I told Doc Mary that I wanted a wonderful, kind doctor to perform my colonoscopy. Not only is Doc Adams a wonderful and kind person, but she did not make me drink all that stuff before the procedure. Instead, I took pills and drank water and ginger ale. I have to say, the night before having a colonoscopy is much, much more unpleasant than the actual procedure itself! Doc Tonya Adams' details are Gastroenterology Associates, 3022 Williams Drive, Suite 301, Fairfax, VA 22031 (phone: 703-698-8960).

and tastes like berry flavored glue. It made me sick for an entire day. Initially, I was excited by the fact that if I had to drink this stuff then I could avoid needles; I was wrong. They shot me full of some stuff that made me feel like I was wetting my pants while someone was holding a hot dagger at my throat. I am also sure to face more needles this week to draw blood before the results are given.

As we approach this next hurdle, some of you have asked me how I am feeling. Well, overall I feel great. Then again, other than the fact that I thought I had a chest cold last March, I felt great then too! I therefore cannot rely solely on that fact as an indicator. The tests, however, have been good. My colonoscopy was clean and my surgeon, who examined me again last week, said everything looks fine. I am therefore more than cautiously optimistic. And, as a general rule and despite having to go through this panoply of fun tests, I have decided that I am going to look at my quarterly tests as another reason to celebrate life.

If the cancer does come back, I'll deal with it then. In fact, there is a small part of me that assumes that it will come back—not because I'm not doing everything I can to avoid it—but because Doc Mary was very serious about the fact that there is a significant risk that it will. Moreover, Doctor Krebs, my excellent surgeon, advised me this week to keep my medi-port for another two years…just in case. Please don't get me wrong, this attitude is not inviting the cancer back nor is it hanging over me like a black cloud. In fact, what taking this attitude has done—surprisingly—is to free me from worrying about it and it allows me to celebrate each quarterly report. As Nesa said to me over the holidays, we don't know if I will have a long life or not; however, what we do know is

that while I am here, I will have a wonderful and happy one. That, my friends, is my celebration of life!

Conclusion More and more, I have come to realize that life is a process, one of change and movement. I find nowadays that I am enjoying the journey more and not constantly reaching for things. This attitude will definitely help me in June, when we have rescheduled our trek up Kilimanjaro. This year, I am not concerned whether I will make it to the top. I only want to enjoy the hike and each day, no matter what altitude I reach.

Sitting here, in my post-surgery and post-chemo world, I can hardly believe that the events of last year actually occurred. Someone the other day called me brave—it wasn't that at all, for I have never been a brave soul. I simply had no choice but to put one foot in front of the other. And I didn't have to do even that alone. I faced this time armed with the most powerful of all tools—the support of my family and friends, and with fantastic medical care. Looking at the faces looking back at me gave me the sheer determination to walk each step of the way, to get up in the morning instead of staying in bed, to find the humor in the certain aftermath of the drugs, and—as much as I could—to share this experience. This sharing was my godsend. I could write about it and get it out of my system, without the fear that people didn't want to hear about it. I could greet people in my life, knowing that they knew what I was going through and we could talk and laugh about it.

I have said that I believe that the greatest growth a person experiences takes place during difficult times. Cancer has taught me many lessons and changed and deepened my relationships with my family and friends. People showed me their best and what it is like

to experience unconditional love. That is why, I am not afraid of whether the cancer will come back again. I remain focused on celebrating my family and friends and embracing life.

As always, thank you all so much for listening,

Lindy

Eight months after finishing chemo: Barafu Base Camp, Mount Kilimanjaro
Mom, Nesa, Pino our friend from the Netherlands, our guide Mohammed,
and my dear friend Roby from New Zealand

Epilogue

A Tribute

Hi all—Many of you, with your big and caring hearts, have called or emailed me over the past week to ask about my nephew, Zack. Zack passed away on February 7, 2006. We remain in a state of shock, disbelief, and profound sadness. I find it hard to talk to anyone outside my family and the radio has uncharacteristically stayed silent in my truck. Some days are better than others; on those that are not, the pain hangs like a shroud over my face, the tears flow, and my mind dully plods over my belief system in an attempt to make sense of why this young man is no longer with us. Zack was my partner in the very fight for our lives. He had always won at things, in that big, smiling way of his, so how can this be? And yet, with such cruel finality, it is.

Each day leading up to the memorial service seemed like 1,000, aching hours long. Family and friends flew or drove in from as far away as Michigan, Colorado, and Montana. They just kept coming, surprising us, Aunt Nan and Uncle Doug, Donald and Elaine, and of course Bob and Mel's childhood friend, Keith. In Cantonment, Zack's name hung in the air. As we walked mechanically through the days, certain things stopped us in our tracks: Bob and I heard someone saying such nice things about Zack at the barber shop (not realizing who we were), the principal and teachers from Zack's elementary school stopped by, the local feed and seed store closed early the day of the memorial service, and the entire community grieved. Whole turkeys, chickens and hams appeared, along with such things as casseroles, salads, rolls, sandwich trays, and of course cakes, brownies, and Zack's favorite cookies. People came to the house in droves.

Bob built a huge bonfire the three nights before the service and people would either hang with us by the fire or in the house.

One of the most lasting memories I have is of the kids. Zack's friends came by to hang out and sit by the fire. On the night of the service, Bob found about 20 of them just sitting in Zack's room, almost as if they were waiting for Zack to arrive before deciding what to do. Another posse of kids staunchly surrounded Nicknack. Several of his best buds took off a few days of school to go fishing, to try to sink the dock in Bob's pond, and to get on the four wheeler to chase after a passing ambulance or police car. Haley hung by the hugs of her aunties and disappeared only when her friends would stop by with their moms.

The memorial service was a testament to Zack's life and to his family. There were rows of kids, people standing in the aisles and flowing out into the parking lot, and his surfboard laid lovingly at the front. After the service, Bob paid tribute in a way that he thought Zack would thoroughly enjoy: reminiscent of their annual 4th of July parties, Bob set off an amazing display of fireworks. It was a celebration of Zack's life.

During the memorial service, people were asked if they wanted to say anything about Zack. Like almost everyone, I simply could not pull myself together to say anything. This does not mean, however, that I don't have anything to say to him, his parents, and Nick and Haley. I do and here it is:

For Zack and His Family

Before turning to Zack, I first want to pay tribute to Bob, Melani, Nick, and Haley. Bob and Mel's dedication to their son was an inspiration to the nurses and doctors who cared for Zack and to those of us who tried to support them. At one point after the first surgery, Bob asked Zack what he wanted and Zack replied that he just wanted to be left alone. Bob told his son that as long as Zack was alive, he was never going to leave him alone; that is just what parents do. And that is exactly what Bob and Mel did 24/7, month after month.

Bob and Mel became well known to the doctors at Birmingham Children's Hospital. Bob would fax Zack's primary doctor multi-page letters, pressing her on Zack's care and giving her ideas on the search for a solution to Zack's illness. With Mel at his side, Bob tirelessly took the doctors to task and demanded that they perform their best in the care of his son. At the final meeting before Zack was transferred back to Pensacola, the most important doctors in the hospital gathered to meet with Bob and Mel. Bob said that he told them that as a simple electrician, he was intimidated by them…and then went right on to point out how they could do a better job. Zack was leaving Birmingham, but Bob pleaded with them to pay more careful attention to those kids who didn't have parents constantly at their side. Moreover he reminded them that they have a duty to instill in those studying to be doctors at the hospital the necessity of excellence in care for kids. Every child who follows Zack at Birmingham Children's Hospital will be better off because Zack—and Bob and Mel—were there.

Nick (15) and Haley (10), the younger siblings, stood by during these past months, watching, waiting, taking everything in, and knowing that there was nothing that

they could do to make life return to normal. They spent hours at the hospital, including Thanksgiving dinner and opening gifts around an artificial Christmas tree. We worry about the effect of losing Zack and living through this time will have on them. I have often choked back tears when I think of standing in their place and the possibility of losing my older brother, my Bob, my Sunshine. Yet, even in the face of our overwhelming sadness, we have to shake off our fears and concerns and focus on them. Nick and Haley come from sturdy stock. They have parents who—as we well know—will do everything in their power to guide them and try to ensure that they have a happy life. They are also fiercely loved by their grandparents, aunts and uncles, and cousins. Although Zack is gone, they at least had him for awhile. And, if there remains a connection between those that have passed away and those of us remaining here (and I truly believe there is), I know with certainty that Zack will be looking out for them. And, perhaps most important of all, they still have each other.

Zack left an indelible mark on my life. During the first year of his life, he began carving a groove in my heart when he and his folks would visit me in New Orleans. At my graduation from law school, we dissolved in laughter when he literally coated me with a projectile vomit from a distance of at least three feet! My love for him grew as I saw and heard about him playing sports, fishing, surfing, and living life with abandon. Over the past 14 months, although I didn't think it was possible, my love and respect for Zack grew. He displayed courage and a dogged determination to get well. Additionally, as his parents served as his primary means to communicate with the outside world, you could sense a significant growth beyond the typical teenage treatment of his parents to one of incredible trust and love. These 14 months, however, is not the part of Zack's life

I want to focus on and celebrate. I want to recall some of the wonderful memories I have of him and his family and some of the lessons his life taught me.

I can't think of Zack without hearing Bob call him, "Zacky-boy," and speak with such pride about things Zack did. I also can see Zack and Nick walking down the beach, while Bob admonished them to take care of each other because siblings are the most important people in one's life. Throughout the years, Bob spent hours with Zack, playing ball with him, instilling in him a love of fishing, and, oh my, teaching him how to drive. From Mel, we could always get the details of Zack's life. She tried to sort out for us which one of the many girls who hung around Zack was actually a girlfriend. She passed to him her love of the beach and dressing up. One funny story came out about this as we reminisced about Zack's life. My parents took the entire Johnson clan on a cruise to Alaska for their 50th anniversary. One night, Aunt Trina and Uncle Mike were heading back to their room around midnight and passed Zack, dressed to the hilt, heading upstairs to try his hand at gambling.

Although Zack was only 18, his life left me with some important life lessons. The first was not anything he did, but how his parents raised him. I have always believed that having a child is like having your heart permanently walking around outside your body. Despite this, and even when they were fearful for his health, Bob and Mel let Zack have his freedom. From the time he could drive, Zack was on the road, hanging with his buddies, going to the beach, and living life large. Stamped on his face in pictures is confidence, happiness, and the invincibility of youth. Knowing that he had this time helps me now that he is gone and serves as a reminder to live and laugh, even when fear lurks from health uncertainties.

Zack was an excellent athlete and student. Undoubtedly, he could have been a school star in playing soccer, football, or baseball. Yet, as he grew older, he decided against the path where he could have received accolades from coaches and the admiration of his peers. Zack instead followed his heart and his passion: surfing. He and his buddies spent hours at the beach, catching waves. Even when his right hand was impaired after the first surgery, he kept trying to surf. Then, there was school. Zack was determined to go to Florida State University (FSU). It did not matter that one and then another of his buddies decided to defer admission or not go at all, he was going. When it became clear that there were too many health questions, threats of seizures, and tests to be run so that he could not be that far from home for the fall semester, he immediately enrolled in Pensacola Junior College. He wanted to stay on track and transfer to FSU. Zack followed his passion, he made his own decisions, and lived his life the way he wanted it to be.

Perhaps the most important lesson Zack left me is that of community. It was a theme of his life and I can see it in the lives of his brother and sister, who have also built strong friendships over the years. Children model their parents' lives and, undoubtedly, the Johnson kids learned the importance of people from Bob and Mel. Zack knew how to reach out his hand in friendship, evidenced by one young man who came to the memorial service just because Zack was the first person to welcome him to Cantonment when he started school there his senior year. Zack knew how to be a friend, being there when friends needed help, laughing with them, hanging out, having fun, and sharing their lives. He chose his friends wisely and they stood by him through the difficult times. Undaunted by the threat of seizures, they picked him up when he could no longer drive. A group of

them rented a house on the beach during spring break and, in the middle of everything going on with Zack's health, they thoroughly enjoyed a "normal" (rather wild, I suspect) spring break. In June, they graduated from high school together. To celebrate, they pitched a tent on the beach and stayed up all night. They came face to face with the worst of it and rode the wave with Zack through it: time after time, as he had a seizure, they called 911, stood by as their friend was loaded into an ambulance, and showed up as soon as they could at the hospital. Their friendship with Zack was so important to them that several have had his initials tattooed on their arms, including one that reads "Gone But Never Forgotten: ZRJ". May we learn from these kids the importance of a strong community, of being there for each other, of helping each other live our dreams, and of standing strong with others as they go through difficult times.

In conclusion, I still struggle with a great deal of sadness and questions of why this had to happen. I don't know whether Zack is somewhere where there is a beautiful beach, with a rolling, perfect surf, but I like to think of him in such a place. I do know one thing for certain. Every time one of Zack's friends runs out onto that pristine white Pensacola sand to catch a wave, Zack will be with them. With every breathe Bob and Mel take, Zack is with them. Every time Nick drops a line in the water to hook a fish, Zack is there. Every time Haley displays an act of kindness toward someone who is sick, Zack will be there. Every time Zack's grandparents, aunts, uncles, and cousins look out over the ocean at the rolling waves, he will be there with us. Every day I fight against the threat of cancer, Zack will be there with me and I will live for the both of us.

Thank you, Zack, for the lessons of love and for a wonderful life to celebrate. And as long as we live, so will you.

Donations for continued research to combat children's diseases may be made in Zackery Johnson's name online at www.chsys.org ("How Can I help?) or sent to:
Children's Hospital of Birmingham, 7th Avenue South Birmingham, AL 35233.

Remembrance

To celebrate Zack's life to Melani, myself, Nick, and Haley actually starts with everyone who we have met and/or reacquainted our friendships with after he became sick the first time. His ability in 18 years to bring so many people around him and us during these last fourteen months who have shown such loving care and concern has shown all of us how special a person he was. The nurses and doctors who cared for him became somehow attached to him even though he wasn't sometimes able to communicate with them. In him, we know they saw a basically good kid who just by being as he was brought forth in them their very best efforts and a feeling of kinship which we have found truly amazing to see these past months. Nick and Haley, being a younger brother and sister, who during their times with Zack sometime elicited the typical treatment of pests were the first people he asked for when he became able to do so. This showed his mother and me that perhaps we did do a good job of raising a tightly knit family who care greatly for each other. Melani and I so needed this gift that Zack so effortlessly gave to us. We--together with all of his Grandparents, Aunts, Uncles, Cousins, the so many kids who have rallied to his side in so many ways, his four sets of mothers who cared so much for him and us not just during these hard times, but all of his life, should realize that a celebration of Zack's life is a celebration of each of our parts in it. We should all grasp and hold close to what he is trying to teach us even now that he is no longer with us. We should all realize just how fleeting life is and live ours as if we don't know what tomorrow will bring. We all should take from Zack the knowledge that wasting time in life sometimes isn't a luxury to be afforded. That to live life being decent and honorable to others is more important than striving for material things. The many parents who knew him will

look at their children and cherish them more because of Zack. And all of us will have the emptiness we feel for having lost Zack filled by the love for each other which he has made possible by the way in which he lived his life.

Bob Johnson
Memorial Service for Zack
February 10, 2006

2007

April 29, 2007

What, Again?!

I pushed my fingers as far into my ears as they would go and closed my eyes tightly. In a singsong voice, I chanted, "I'm not listening, I can't hear you!" Doc Mary's kind face swam before my eyes as she delivered the unwanted news: another round of chemotherapy. No matter how much I wanted to take this churlish and childish response to the news, there is no getting around it. The "grumpiness" that I'd been experiencing in my lower tract was not simply indigestion or overly spicy Mexican food, but a reoccurrence of the cancer. Thus, while the 2 mm spot on the liver would not have been enough to warrant more chemical bombardment, the two new spots on my colon are. Here we go again.

My psyche went into a full court defensive position upon hearing the news and I began bargaining with Doc Mary. I was scheduled to go to London at the end of the week and she agreed that I could start treatments after the trip. Once that was secured, I then tried to figure out how I could fit my chemo schedule in between the many plans I'd already made and the life I intended to lead. David was far more practical, asking questions, trying to comprehend fully why this had happened, how she knew there was a need for more chemo, and how many and where the spots were. I clutched his hand, pretended to be okay with the news, and checked out of the discussion.

Life went on as normal during the rest of the week and the fact that I had to undergo chemo seemingly became just an interesting story…almost like it was a story about someone else. While I once again let my stalwart sister, Nesa and now David call my nearest and dearest with the news, I carefully managed how I let people at work know

so that I could ensure that I would still be able to work on—and in one case complete—particular issues. Thus busily occupied, it took me several days before I realized that not once did I ever say that the cancer had come back. Instead, I delivered the news in terms of having to once again get chemotherapy, obviously allowing the listener to draw the inevitable conclusion. Perhaps it was because I wasn't ready to accept the news or maybe because I didn't want to think of the cancer cells once again having a party in my body. However, with this realization and the steady march of time toward the treatments, I began to tell the truth: the cancer has returned and must once again be dispatched.

I found out the news on Monday, April 9th, and had a new port installed on Friday, April 13th. Luckily, long ago I had gotten over being superstitious about Friday the 13th. Besides, the name of the doctor installing my port was Doctor Varma, "that's karma with a 'V'", he said, so, how could anything go wrong? Yet, despite this welcoming reference to yogic principles, Doctor Varma was anything but impressed when I told him that I intended to leave in two days for a four day yoga retreat (yes, I abandoned the plans to go to London shortly after the words came out of my mouth and thankfully my wonderful boss, Poppy, and the U.S. delegation were entirely supportive of this decision). He sternly told me that I was not to do any physical exercise for at least a week. I reconsidered my plans for only about five minutes as I was wheeled into surgery. It was critical to me to go to Yogaville (yes, this place does really exist—a little slice of heaven on earth) and bring my body, mind, and soul together. Moreover, I figured that with my training as a yoga teacher, I could protect my shoulder where the port had been installed.

After four days of yoga and four fabulous days camping at Assateague National Seashore with Nesa and David, my spirits were high and I was ready as I was ever going

to be for the next round of treatments. I had my backpack packed with socks, a hat, a blanket, my pink book where I had written questions and record such things as my vital signs, a book, my music, and of course snacks and water. Team Smiley was there to greet me: Kristen Smiley my wonderful primary nurse, Sandy with her endless hugs, Triscilla, and Maria. While one of you remarked to me that at least I would know what to expect this time around, I am finding that this is just never the case in the cancer world…and, even if it was, I'm not sure that knowing what the effects of chemotherapy are is a good thing! In any event, things have changed. My port is now about half the size of the one I had before and there are some new anti-nausea drugs available. Doc Mary also indicated that although we will be using the same treatment protocol for the first four times, there are now some pills on the market that we may try to take the place of that awful, whirring box (which, you will recall, is attached to me for 46 hours and injects chemo every 15 seconds). Additionally, instead of getting two drugs on Monday, the box with a third drug from Monday through Wednesday, and the final wonder drug, Avastin, on Wednesday, I received all of the drugs on Monday. That meant that we were at Doc Mary's from 9:15 until almost 4:00. It was a very long day—mostly for Nesa—because I, of course, managed to take a couple of very good naps.

While this week has been hard and I have fought everyday against throwing up, I am relieved to say that one treatment is now behind me. In fact, because it helps my attitude, I have decided to count the treatments as 13 down (the 12 previous treatments and one this time) and only 11 to go—that means I'm more than half way through already! I have found that my ability to forget unpleasant experiences shielded me from remembering the excruciating details of a treatment week: the bathroom issues

(including fire diarrhea), the inability to drink anything cold for 10 days, the pervasive metallic taste, the tingling in my hands and feet, and, something I truly don't remember, severely chapped lips which to me seems like the chemicals are burning me from the inside out. Despite all of these physical discomforts, I must admit the hardest thing has been the necessity of unwinding the plans that I had made and once more scaling back on my activities. I don't like to accept physical limitations nor do I easily accept staying in bed and feeling ill. So, once again, I must employ the lessons taught so well in the yoga world, which is to live each moment for what it is. On that note, someone asked my sister what my prognosis is. Funny, that thought had never even crossed my mind! I—like you—have no idea how long I will be alive. What I can promise, however, is that I will continue to live life to its absolute fullest and I hope that you will too!

Thanks once again for listening. Live life large, laugh with abandon, and love unconditionally,

Lindy

Walkabouts

Hi all—Rain, shine. Positive, negative. Ups and downs. Life's twists and turns. There are times when it feels that life is very much like a roller coaster, especially when the brakes are released and the car is plunging downhill. I never liked this downhill plunge and I don't like even admitting to downhill slides in life in general. For there is a tendency when things start to go awry, and then when more bad things happen, to finally say, "what next?!" or to enumerate everything going wrong. I strongly resist this urge—and will continue to do so even in this email—because I believe that such negative thinking only attracts more negativity. My Mom too is a guardian against such thinking and, since she has been with me the past 2 ½ weeks, we have found things to laugh about and she has created a profusion of flowery colors all around my house to lighten my spirits. Yet, I will admit, it seems that there is a little black cloud hanging over 6912 Duke Drive. While I am doing my best to steadfastly work through and feel each event and then move to a more balanced place, I am struggling and looking for an umbrella or better yet a strong ray of sunshine to beam down on me.

Relay for Life On the positive side, one of the highlights over these past few weeks is the absolute lift that many of you provided me. By contributing money to my efforts to raise money for American Cancer Society, you reaffirmed my life and helped me to raise money so that hopefully some day soon they will find that all important "maintenance pill" that I need to survive. Thanks to you, I was the top fundraiser in the Damascus Relay for Life, raising $6,575. Our team, which I laughingly say was made up of moms, daughters, and David, raised over $19,000 and Relay overall raised over $236,000! With this tenth anniversary, the tiny town of Damascus, Maryland has raised

over $1.5 million for the American Cancer Society. These efforts as well as those throughout the United States and the world make a huge difference, especially since funding for cancer research has been slashed in the President's budget and by Congress in the last several years. Thank you, thank you, thank you for your contribution!!

The event itself was on a Saturday at the Damascus High School track. I was surrounded by some of the people who I love best in the world, Mom, Sarah (my childhood friend) and her family, and David. The event started out with a Survivors and Caregivers' Luncheon at which I gave the keynote speech. As many of you know, I actually enjoy public speaking, but I had never before had to speak about something so personal and about an issue that meant so much to the audience. And, while this may sound odd, it was also a defining moment to stand in front of a group of a people and say "I am a cancer survivor." I'm not exactly sure why, but it was difficult and drew attention to the fact that I will always be different and that life just isn't the same anymore for me. I can't explain it, but there was a psychological shift that I went through and perhaps that is why those in Alcoholics Anonymous use this technique. Given that every cancer survivor in that room had their own unique story, I decided to focus my speech on the similarities among cancer survivors and what it means to be one. If you are interested, I have included the speech at the end of this email.

The day was great fun. There was an opening ceremony and the walk started with a lap by the Survivors. In the center of the track, there were a wide variety of events happening throughout the day and all money raised went toward American Cancer Society. Each team also had a place alongside the track to hang out or sell things to raise money. The first thing that Mom wanted to do was to take a sledge hammer to an old car

that had written on it, “Beat Cancer.” Let me tell you, she definitely beat it! The entertainment included these amazing jump ropers and gymnasts, and multiple rather loud musicians. One of the things I love about Relay is the participation by the kids. There were several teams made up exclusively of kids and it was so heartening to know that they cared enough to raise money for this important cause. Our team too included kids and my little 7 year old friend Nicole raised over $1,400 herself!

At 9:00 p.m., the luminarias—white bags with candles in them—rimmed the track. Each bag had a person’s name on them, either In Memory Of or In Honor Of. Unfortunately, I had more than one person for whom I had purchased a luminaria. It was also moving to see my name on a bag and Sarah, who had of course purchased it for me, and I had a long hug in front of it. I was also the keynote speaker at the luminaria ceremony. I had almost declined to speak at this event, because I didn’t think I would be able to strike the right chord of being somber in the face of the lighted reminders of so many people who have died. However, instead of focusing on that aspect, I focused on the gifts of cancer and the fact that every bag lit was a reminder that someone at the event cared and was raising money to fight the disease. In short, I focused on hope. And, while I was speaking, in the stands, the lit bags that had spelled out “HOPE” were changed to “CURE”. It was such a moving experience. For all of you yoginis, I ended my speech with three “OMs”. OM is the universal sound, a healing sound that I believe can bring your cells into their natural alignment. The reverberation of “OM” from the 200-300 people who were there was fantastic and I almost felt as if I was buzzing afterwards. It was an incredible, uplifting experience. Although I spoke extemporaneously, the gist of that speech is also below, if you are interested.

Sparky Two weeks ago today, my little, wonderful cat, Sparky, went on a walkabout. She had been so anxious to get outside (sounds like me so how could I be mad at her?) and then one day, she just disappeared. It is even more curious because there were no doors open. For those of you who have been to my house, you know what a personality Sparky is. We got her from the pound during my first bout with cancer and she soon took over the house. She is incredibly talkative, greeting me at the door whenever I came in, and, about 98% of the time, wherever I was in the house she was too, whether it was behind my computer as I worked, on the edge of the bathtub to make sure I didn't drown, laying on me to knead the area where my cancer was (yes, really), creating a diversion for me when I truly felt bad during treatments, and meditating on my lap with me in the morning. Each night, she would tell me when it was time to go to bed and we would make our way up the stairs, two at a time, and she would lift her head for a kiss and wrap herself around my legs, chattering at me all the while. As you can probably tell, with her gone, there is a huge hole in my life and my heart is heavy. Mom, who is not even a cat person, has walked miles in the neighborhood, putting up signs and talking to the neighbors (which has had some unfortunate results like when one neighbor called and offered me the stray hanging out around her house, like cats are fungible!). David too has gone into and under people's sheds. Gracie, David's kitty, looks lost and spends hours in front of the door, as if she is waiting for Sparks to come home. We all miss her.

Even with her disappearance, Sparky continues to teach me valuable lessons. First, in trying in vain to reach a balance and not become so upset that it would affect my

healing process, I revisited my beliefs about ownership. I do not believe that anyone ever owns anything, especially another living creature or even the ground or property on which we live. It is ours for awhile, to enjoy, love, and maintain; however, ultimately, everything is free and has its own purposes in life. Second, one of my strong spiritual beliefs is that the Universe will lead us to the place where our energy is needed. Therefore, perhaps the wonderful energy that Sparks had shared so lovingly with me was needed for awhile some where else. I was comforted when at least two of you echoed this thought.

These thoughts, while initially comforting, did not shield me from the harder lesson. That lesson is the one of simply feeling very deeply when there is a loss of someone or something in your life, especially someone or something that you see and interact with everyday. And I cried and still cry, hard--for I miss her and this blow is simply undeserved and unwarranted, especially right now. With my tears for Sparky, I learned another lesson. You may remember that during the last round of surgery and chemotherapy, I said that I had never sat down and really cried about anything. I had "mini-crying" sessions when something hurt, but the floodgates had never been opened. Thanks to Sparky, they now have been. I have cried because, like the Sparky situation, this reoccurrence is undeserved, arbitrary, and frankly painful. I have cried after certain bathroom bouts have left me weak and exhausted. I guess it is lucky that the tears cannot come during treatment week, because the backs of my eyeballs hurt too much—so during these weeks, I am sad in my heart, mostly because of Sparky and also too because of this damn disease.

I know that I must come back to my balanced and positive place, because I firmly believe that this is the only way to heal. Yet, I haven't been able to reach out to respond to those of you who have offered help during this time. I am struggling with how to come to grips with it and I hang on to stories where other cats have eventually come back. Perhaps the hope in that thought will be the key to reassert my usually buoyant spirits. For now, I must just accept that life isn't about what you may want or need, it just is. I do know, however, that I must get a grip on my attitude for something must change, because—after yesterday's visit to Doc Mary's—I know that it is having an affect in my body.

Side Effects and Health Hiccups I now refer to my treatment weeks as going to the "Land of Healing" instead of chemoland. I am working on instilling the thought that, even with the nasty side effects, the drugs lead to health and are therefore good; even with the side effects, I am trying to view them only as evidence that the treatments are working. As I said in my last email, the week following my 13th treatment (or first of the second round) was very difficult. Of course, I was busy figuring out why that might be and how we could change it. Of course, I was completely off in my analysis and Doc Mary had the answer. She and Nurse Jen reviewed my former treatment protocol and the one I had been given the last time around; apparently, during the intervening 18 months when I was not getting treatments, they had increased the levels of Oxilplatin (yes, a platinum-based drug). This increase may have been responsible for the severely chapped lips, the pervasive metallic taste on my tongue, and for feeling nauseated for almost the entire two weeks. Since I had responded well to the first treatment cycle, Doc Mary agreed to reduce the Oxilplatin down to the original level. Thank goodness and it made a

huge difference overall in how I was feeling. Regardless, it is still necessary to expect the unexpected with these treatments. The bathroom issues lasted on and off for the entire two weeks, there was a rawness "down there" that made it difficult at times to walk or sit, and for most of the two week, my voice would disappear later in the day. The "sexy chemo voice" effect was perhaps the most difficult, because it took an effort to talk and thus was like a small pinhole leaking my bubble of energy.

On top of the "normal" side effects, my energy was also being taken up with worry and pain caused by an inch long type of blister on my left hand. It actually looks like snake skin and the pain from it radiates all over my hand and one time went down to my elbow. I discovered it just after we went out kayaking, although who knows where and how I got it, especially since my immune system is now shot from the drugs. I called Doc Mary's and they sent me off to see my dermatologist, who did nothing except lance it, put a band-aid on it, and tell me to call him if I awoke to find 400 of them covering my body. Hmmmm It hasn't gotten any better and Doc Mary made an appointment for me today with an infectious disease doctor.

I thought that this blister thing was enough of an oddity to present Nurse Kristen and Doc Mary with yesterday, but no, my body had other thoughts. For the first time ever, my port gave Kristen problems and would not allow her to draw blood to test before we started the treatment. Lucky me, she then had to take it with a needle from my arm—have I mentioned lately how I hate needles? She then came back with the further bad news that my white blood counts are low and that we may not be able to do the treatment. Unconsciously, I gripped the arms of the chair and, after the fleeting thought that it might be nice to go on feeling rather normal, I shook my head. I had to have the treatment. I do

not want to prolong this treatment cycle, people have made plans to be with me on certain dates, and I have made other plans that I do not want disrupted by a change in the schedule. Well, Kristen told me that if I were to get the treatment, I had to promise to inject myself for five days with a medicine that should help replenish the white blood cells. Sigh, that thought horrified me. Only two things mollified that horror. First, she told me I could use my Emla cream, which I use to numb the port before she puts in the needle, and second, David has offered to do the injections. As with anyone approaching me with a needle, I demanded to know his experience in giving injections. Even though he said that he has only given his cats injections, I decided to trust his gentle nature and love for me and besides, I really have no choice but to do it myself. So, this should be a very interesting part of the cancer journey!

Conclusion So, while there are some things in my and David's life that I would rather not be happening, I am not going to sit here and dwell on them. I will say that there have been some definite energy drains and that I am struggling to maintain a positive attitude. Luckily, my Mom is with me and when there is something bad going on, she usually comes up with exactly the right comforting words or a funny quip to make me laugh through it. From my perspective, as I told a friend the other day, I just wish something unexpected and good would happen, something out of the blue, something to lift my spirits. Of course, the best thing would be for Sparky to come home, but she has to do it on her own time and hopefully that will be when she is done with summer school.

All the best to each and every one of you,

Thanks as always for listening,

Lindy

On Being A Cancer Survivor: The Different Similarities

Lindy S. Johnson, May 5, 2007

Survivors and Caregivers' Luncheon

Good afternoon! Survivors in the room, I know you can relate when I say I AM SO GLAD TO BE HERE TODAY AND SO GLAD TO BE ALIVE! Let's give each other a round of applause and applaud life!

When I began gathering my thoughts to speak today, I thought back to the courageous woman who told her story at last year's Survivors' Luncheon. I realized that each of us has our story and that cancer with its insidious ways affects each of us individually and uniquely. And, although I think my story is fascinating because it's my story, I wanted to do something a bit different. I want to focus not on one individual story, but instead on our similarities. That is, what is means to be a Cancer Survivor.

The first things are perhaps the most obvious. Each of us survivors has had to hear those three unwanted and life changing words, "You have cancer." We have then had to deal with the fear of the unknown, the worried faces of our loved ones, and the

uncertainty about how this disease is going to affect our lives. We also have to come to grips with that unavoidable question of death: what we think about it, whether we're ready to face it, and whether we are going to live in its grip or grasp life with both hands. We also have to deal with a shadow that follows us around called "reoccurrence."

Then come the physical issues. For as many types of cancer that there are, there too are just as many treatments. Surgery, radiation, and a wide array of chemical cocktails. Despite these differences, there is one basic similarity: they all are unpleasant, unwanted, and of course undeserved. The pain caused by these physical issues often lead us to live one step at a time, moment to moment, and dreaming of a tomorrow that is pain-free.

The mental issues too cannot be discounted. Each of us must develop the mental fortitude to survive, to overcome the physical difficulties and limitations, and to dream to live. Most cancers also play cruel tricks on us by forcing us to confront the disease each morning in the mirror and in the faces of even those who pass by us throughout the day. For those of you who know me, you know that it is uncharacteristic for me to dwell on the difficulties of cancer. I attribute this to my Mom, who is with me here today from Michigan to take care of me through my next two chemo treatments. She is the embodiment of a positive attitude! While it may often be difficult for cancer survivors to find a bright side to this disease, we all know that to survive, a healthy mental attitude is necessary.

The second thing we have in common is that we have caregivers. Let's give them a huge round of APPLAUSE!!! Where would be without them? Our caregivers are there to give us hugs, believe in us, cajole us through each treatment, cook for us, and just be

with us. The flow of unconditional love from these people is truly amazing. When I was going through my first round of chemo, I was so preoccupied with everything going on that I never stopped to focus on how all my wonderful caregivers were feeling about the fact that one of their loved ones had cancer. You know, in many ways, I actually think it is harder to stand by watching someone you love fight the disease than to have it yourself. Even though the caregivers try to do everything they can to help, there are some things that they just cannot do. They cannot take the treatments, they cannot take away the pain, and they cannot change the outcome. While these things are true, I think I speak for all of us survivors when I say these things are small compared to the love and support that we receive from our caregivers, for the unconditional love that flows our way from you each and every day, for helping us to fight to remain in your lives, and for simply standing as a witness beside us. Thank you, thank you, thank you the caregivers in this room!

The third thing that we all have in common is that we are here, participating in Damascus Relay for Life, and that every person who we see on the track today is here for us! Every person who worked long and tireless hours to organize this event, those who spent time away from their families doing such things as sitting in front of Safeway to raise money, and those who worked to serve us lunch today have all done this to find a cure for cancer and therefore they have done it for those of us in the cancer community. Let's give a huge round of applause to all of those people who worked so hard to provide us lunch today.

Finally, to be a survivor means being part of the cancer community. Believe me, this is never a community that I or any of us cancer survivors ever wanted to be any part

of! However, now that I am here, I will repeat what I said at the beginning, I am so glad to be here today. I am glad to be here today because when I look out at this room I don't see the evidence of an ugly and hurtful disease. I see hope, passion, and a strong will live. I am so very proud to be a part of this community, part of Damascus Relay, and I am so very glad that I am a Cancer Survivor.

Gifts of Cancer

Lindy S. Johnson, May 5, 2007
Luminaria Ceremony

On the very day of my 44th birthday, I was diagnosed with Stage IV colon cancer. I had 8 pounds of fluid in my right lung and they removed 8 tumors throughout my body. Silly me, I thought I had a chest cold and that the lump in my stomach was simply a fibroid. I will admit to you that while sometimes even now I wish that the gift that came calling that day was not cancer but something shiny wrapped in beautiful paper, I do believe that along with all the things about cancer that are painful and difficult, I have received some very valuable gifts from this disease. And it is about these gifts that I want to talk to you tonight.

Unconditional Love: The first gift that I continue to see—and it is evident tonight as I look out and see the bright light of the luminarias—is that of unconditional love. Yes, I was aware that I was loved before cancer, but when cancer struck, people that I had no idea even knew who I was wrote me cards in support, sent me gifts, and gave me words of encouragement. It is this love and support that I continue to rely on and cherish today.

Hope: Just before I received my diagnosis, I was very upset with the state of the world and, contrary to my usually upbeat personality, I was depressed and angry about it. Having cancer changed that attitude. Instead of seeing the world as an angry, hateful place where bad things were happening everywhere, I began to see people reaching out to help each other, people caring about each other, and people making time for each other. I saw hope and, looking out at all of you in the stands that are here helping to find a cure for cancer, I am overwhelmed with this feeling of hope. A cure will be found and I won't have to worry about a reoccurrence.

Appreciation: Cancer made me even more appreciative of the gifts I have been given in this life. One of those was overall great health. That helped me weather this storm better than had I already been sickly or not had as much stamina. Additionally, and I will think my mom and dad for this, is a positive attitude. In my family, we were instilled with a can do attitude and to look for the best in things. My mom is here in Michigan to be here with me for next two treatments, and if any of you have met her today, you will see where this attitude comes from.

Time: As with many people, life has become very very busy and we race from one thing to another, rarely taking time to sit on the porch and chat with people. Cancer gave me this gift. While there are times that I wish time would speed up to get me through how bad I'm feeling, I have had to slow down. That means that I have spent many wonderful, wonderful times with family and friends that I probably would not have done before. I will also admit during one of those times that I slowed down, I met the love of my life, David, who is also a cancer survivor.

Community Involvement: Prior to cancer, I always said that I wanted to do some volunteer work, but never seemed to find the time to do it. I would simply give money. Alternatively, I watched my childhood friend Sarah Ball working so hard each year to raise money for Damascus Relay. She connected with her community, supported it, and has made a difference to those of us in the cancer community with the money she raised. While before I simply stood in awe of her efforts, we now work side by side, giggling as we used to as kids as we work to make our money raising goals.

Connections Finally, the last gift that I will mention tonight is that of connections with other people. As I look out and see the many, many luminarias, it evident that cancer connects people and brings out the best in people. For those that have fallen in the face of this disease, the lights shine brightly and those people still live as a light in our hearts. For those of us that are part of the cancer community, these lights shine brightly as a symbol of unconditional love and hope that we will find a cure and that those of us that have had or, as in my case right now have, the disease will be able to live a long and full life.

In conclusion, I would like to do something with you that is part of my yoga training. From the ancient yoga traditions, there is a sound that when said is known for its healing properties and is said to be the sound that connects everything in the universe. That sound is O- M or OM. When you say it, it is supposed to set up a vibration in your body that brings your cells into their natural alignment. When it is said in a group, it is even more powerful indeed. So I am going to lead you through it. We are going to do it three times in. So when you have expelled your first breath take a second and then a

third time. Please take the hand of the people next to you, close your eyes. Take a deep breath in…….OMMMMMM

Repetition Times Three

Hi all—Life in the cancer world continues to tug at and tease my resilience, test my flexibility and mental fortitude, and teach me even more life lessons. Over these past three weeks, the unexpected has once again occurred and reminded me that the unexpected is what is to be expected with this disease. It has forced me to face my desire to be in control and my struggled attempts to force life to fit my whims and desires. Cancer has a way of ripping apart and destroying one's expectations for how one's life is going to unfold. As it did so to my life over these past weeks, gradually, a resounding realization about my life has occurred.

I have always maintained the belief that if an answer comes up three times—whether researching a legal issue or just in the normal course of life—then it must be true and it must be the right answer. These past weeks, the message that has come through quite clearly from the Universe is that I need to rest and that, almost down to the cellular level, I am deeply tired. I'm not sure whether the tiredness is from the weight of the disease or that the disease simply forced this understanding. I will admit, I have led a full and fun life both at work and at home that some may actually call frenetic. Multitasking comes easily, each day presents new opportunities and activities, and, as a result of overly full days, I effortlessly and quickly fall into a deep, dream-filled sleep. Sitting still, except for meditation, never happens. I don't recharge just by being. Thus, over the years, it may be that there has been a slow leak on my reservoir of energy. As anyone who knows me must realize, this is not easy for me to accept because my mind is constantly racing with what I could or should do. Yet, somewhere in the recesses of my

soul I have recognized that now, rest is not only mandatory to once again beat this disease, but to build the strength and energy for the next phase of my life.

Yogaville My third chemo treatment took place the week before Memorial Day. As you know, before starting treatments I had visited Yogaville, a wonderful yoga ashram just south of Charlottesville, Virginia. I had discovered that a wonderful singer was going to be there over the long Memorial Day weekend. Even though all the tent sites were full, I put my name on a waiting list and, when a site became available, David and I made plans to go. I soon began to question my judgment, especially since my white blood cells (or WBCs as I now fondly call them) were low and because we would have to ensure that my daily shots of Neupogen would be refrigerated. In fact, on the Thursday following treatment, I felt as if a truck had rolled over me and I could barely lift my chin off the table. In between naps, I anxiously awaited for the delivery of the Neupogen shots from Kansas (!). They arrived just before we left on Friday and, after receiving an injection, we were on our way.

Luckily, my worries about going were unfounded and the weekend resulted in many unexpected gifts, including the first message that I needed to rest. The singer that we went to see is called Krishna Das and, although American by birth, he is a reknown singer of kirtan. For those of you who are not involved in the yoga spiritual world, kirtan is the repeated chanting of the divine. Undoubtedly, some of you are probably now raising an eyebrow! In kirtan, the name of the divine is not actually in English, but from Indian spiritual texts and it is done by call and response. The instruments for kirtan are something called a harmonium, a beautiful instrument that looks like an accordion but sits on the floor, and tabla drums. Singing kirtan is nothing like singing hymns in church,

but more like being in the gospel tent at the New Orleans Jazzfest. The chant starts slowly and then builds to a point where the audience is moving, clapping, and dancing. It is great fun. For me, the unexpected side effect of singing kirtan was that the vibrations of the music somehow soothed the chemicals in my body and I have never experienced such a painless and smooth transition after a treatment. That alone was worth the entire trip!

The unexpected and by far the most moving part of the weekend came as a result of a speech by a Yogaville Swami (a yoga renunciate) who gave a morning presentation on ways to reduce stress. I thought we should attend because, of course, it would be good for David! However, from the moment she began speaking, she touched and probed many things of meaning to me, from an incredible book given to me by my boss during the first round of chemo (Man's Search for Meaning) to various life experiences that I had also experienced. When she referred to the fact that she had just come back from a week long retreat where she worked with cancer patients, David squeezed my hand. He then bird-dogged her at lunch following her speech and asked her to meet with us. To my complete surprise, the minute we sat down with her in a secluded yoga room, I burst into tears and all my practical questions about the where and when of the retreat vanished. With her wise words, embracing love (for two complete strangers!), and healing ways, she helped me face and deal with the ebb and flow of emotions. When finally I was quiet, she simply said "rest and the answers to your other questions will come in time." I breathed deeply, surprised by this response. Yet, as they sunk in, it almost felt as if someone had given me permission to stop moving, to stop having to get things done, and to accept that the only thing I had to do was be.

Despite this initial feeling, it immediately became difficult about exactly how to put her words to work. I will admit, I resisted and it continues to be a struggle to define what "rest" means. In fact, I woke David up in the middle of that first night, concerned about a meeting I was supposed to attend at the United Nations in New York. As opposed to the meetings I have attended for years in London, I had no idea of the rhythms of this meeting, the number of people vastly exceeds those who attend the London meetings, and frankly—undoubtedly because of my personality and views on the issues to be discussed—the U.S. delegation itself could prove to be fractious. I spun out different scenarios, attend but only work during the day (none of the certain midnight or later sessions) or attend part of the week, but as David shook his head, I realized that if rest meant anything, it probably did not include this trip. I now have to choose quite deliberately where to expend my energy and on what issues I think I could or should expend energy to make a difference. As it turned out, my body itself nixed any possibility of going to New York as it gave me the second message to rest.

Platelets The following weekend, my wonderful friend and caregiver, Monique, arrived from Montreal to see me through my next treatment. With the shots I had received and all the energy (and prayers) that many of you had directed toward my WBCs, I was confident that there would be no problem receiving treatment. The needle was put into the port, Nurse Kristen drew my blood, and Monique and I laughed and joked as we waited for her to come back with my batch of brew. Apparently, not looking forward to hearing my reaction, Kristen winced as she pulled aside the curtain to my room. She shook her head, "No treatment for you today!" I looked at her incredulously

as the full impact of her words hit me. Apparently, my white and red blood cells—for which you can receive shots to help your body produce more—were fine. Instead, my "platelets" were dangerously low. I searched my brain, trying to remember back to my high school biology class. I couldn't remember anything called platelets! So, as I tried to convince her of the need to have the treatment, Kristen patiently explained that platelets are critical to the blood's ability to clot and, if for some reason I were to experience internal bleeding, I could bleed to death. Yikes, that was sobering. Even I could not fight that.

This new development had more, unwanted consequences which Kristen, in her usual, thorough way, proceeded to tell me. I had, of course, scheduled my chemo treatment as far out as they were keeping track of appointments. When Kristen discovered this, she rolled her eyes and all of those appointments were removed. Now, they will only let me schedule one treatment at a time. Moreover, I am not to take my expensive, anti-nausea pills before coming in, because the treatment might not happen. Instead, I am to take them after my blood is drawn and, if it proceeds, then I will take them. Doc Mary has also again reduced the level of my Oxilplatin in the hopes that this too might make a difference. Apparently, these issues with WBCs and platelets are not uncommon when a person is getting chemo and Kristen said that I had simply been very lucky that it had not happened during my first round. This time, however, my body has already been hit and it needs time between treatments to recuperate. In delivering the second message from the Universe, apparently the only thing that I could do was to rest and let my body heal.

I will admit that this news hit me hard and it took some time before I could digest it, along with its ramifications. Luckily, as we ate our lunch by the Potomac, Monique talked me through it and, as with so many of the wonderful people surrounding me, helped me to see the positive aspects of it—the most important of which was that my body needed time to assimilate the drugs and that I would probably withstand the treatment better since we had to wait. Not being one to give up on worry easily, I went through my concerns. First, I realized that my carefully built schedule of caregivers—some of whom had already purchased plane tickets—may be disrupted. Of course, that was more of a concern to me than it ever was to them! Also, the disruption meant that I quickly had to put together caregivers for the following treatment week. Again, my worry and concern about this issue were unfounded and with three phone calls, I had three wonderful local caregivers (Sarah, David, and Karen) lined up. Mom too had immediately cleared her calendar and actually seemed almost disappointed when I told her that others were already scheduled.

Second, the delay meant that the last treatment would not be the first week in October and, if there are repeated delays, I could be undergoing chemo for an undetermined length of time. Psychologically, this is hard. It so helps to know—or at least think I know—when this all could be over. Finally, and perhaps most importantly, I want this cancer out of my body and I am concerned that the delay in treatments will somehow affect our ability to kill it which in turn may result in the need for more treatments. Argh. This concern remains and I have to wait until next week when I see Doc Mary to talk to her about it.

So once again, the disease dictated the course of events in my life and left me feeling acutely vulnerable in its grasp. Was it trying to teach me flexibility? Well, if it is, it's not a lesson that I am learning easily and frankly it seems that people are only truly flexible if they don't care very much about an issue, they care more about another person's happiness so are willing to be flexible to accommodate them, there is simply no way forward without finding some way to work together, or a person is smoking something and just doesn't care. Hmmmm, I think my spirit has some work to do on this one or more yoga is required to gain flexibility!

Left with the week gaping before me with only the admonition to rest, I fell into my old pattern of making plans. Since I would be tempted to do things if I stayed at home, I suggested we retreat to the place that soothes my spirit and the only thing to do is walk on the beach and nap. We thus left to camp for a few days at Assateague National Seashore the next morning. If you have never been there, I strongly encourage you to go. The beach is beautiful, broad, and long and the camping is just over the dunes from the ocean so that you fall asleep listening to the crashing of the waves. We had a wonderfully restful and—except for the exceptionally hungry wild pony that managed to bite open our food bin and eat our oatmeal—uneventful time.

Prana and the Breath The last message from the Universe also came from a yoga swami, an Australian medical doctor who works with cancer patients as well as others with serious illnesses. Swami Shankradev and his partner, Jayne Stevenson, are visiting several cities in the States to give seminars on powerful healing techniques that focus on the breath. While he gave me many insightful pieces of advice particular to my situation, one of the most important was to attend their weekend seminar. Despite having

other “had to do” plans, in the face of a promise of healing techniques and my loved ones’ desire that I participate in anything that I thought might help me heal, the obstacles fell away and I spent the weekend learning and practicing techniques that left me glowing from the inside out with energy. For this, I owe a huge thank you to my dear friends, Sonia, Philip, and Cheryl, for facilitating my meeting with Shankradev and attendance at the workshop.

So, what is this all anyway? Well, have you ever stopped to think about something you do every minute of the day? We can go without food, water, and shelter for days, weeks, and maybe even months, but without breathing we would be gone within minutes. In yoga, “prana” means life force and it is easy to imagine simply at a physiological level how the breath—with its introduction of oxygen—provides the very life force of the body. The manipulation of the breath (called pranayama) in yoga is used to achieve various things. There are techniques that can be used to balance and calm the mind—lately I’ve been using one of these techniques to help me go to sleep. Other techniques actually work much better than Starbucks’ strongest brew and leave my cells buzzing with energy. And still others are available that help cool—or heat—the body. Even before this wonderful weekend, I had always referred to pranayama practices as the “candy” of my yoga practice. It therefore was very easy for me to accept that, of course, the use of the breath could be used to heal. The only question was how.

It would be a daunting task for me to think that I could summarize the wise words of Swamiji and Jayne and thus I won’t even try to do so. Instead, for those of you who are interested, I urge you to look at their website (www.bigshakti.com). There are a couple of things, however, that I want to share. First, Swamiji was able to convey the

logic behind why yoga practices are so important for overall health. As we all know especially if we sit too long in one place, energy gets stuck in certain places and the yoga asanas help to ensure a free flow of energy for use by the body. Second, the method Swamiji and Jayne teach focuses on directing the breath into certain areas of the body with acute awareness. I am now using this awareness to try to remove energy blockages with the breath, which for me not surprisingly occur in my lower tract. Lastly, there is the practice of Yoga Nidra which I mentioned to you during my first cancer fight. Everyone —especially those of us in urban settings but indeed all of us who experience constant stress day after day—need to do Yoga Nidra as often as possible. It is a deep, deep relaxation practice that can be done by anyone. (You can find Yoga Nidra CDs, including on the above website.) Very few of us take the time to relax deeply anymore: we keep some part of our being active at all times whether it is watching television, running kids to their various activities, or even talking on the phone. None of these allows the body a chance to rejuvenate and recharge. Yoga Nidra facilitates these things and, after doing it, you will be so refreshed. So, please for your health, check it out!

Conclusion Thankfully, last week, my blood was fine and I was able to have another treatment, so only eight more to go. On the days following the treatment, waves of tiredness washed over me and I was poignantly reminded of the messages I had received. I will admit, it is still difficult to figure out how to "rest" and address this tired feeling. Some things, of course, are obvious, like trying to take naps and stop before my head is pounding so hard that I can't see straight. But think about it, have you ever stopped to figure out what in your life drains your energy? You are probably thinking, "WORK". And yet, can you be more specific and, in doing so, change even one thing to

make it more enjoyable? Some examples for me are cutting way back on the amount of time I am spending on the phone and rely more on getting messages via email. Also, although an avid news junkie, I have gone on a "news blackout." With one of my wonderful nephews in the Marines in Iraq, I just can't face the rising toll of casualties. To my surprise, this news blackout actually makes my days lighter and I can count on my Dad or brother to let me know whatever news I need to know. So, again, I'm back to taking each step as it comes, but I am trying to slow down, breathe, and rest. I hope that each one of you will take some time *today* to do the same!

As always, thanks for listening, be well, laugh often, and love unconditionally,

Lindy

Reoccurrence

Hi friends---I am sitting at my dining room table in the early morning hours, watching the squirrels play tag up and down the tree in my backyard while a humming bird darts in and out of view. As the air begins to have that feel of summer slipping by, I marvel at how wonderful and resilient life is. I have survived another treatment this past week and perhaps it is the pernicious tiredness that settles in after a treatment that is now contributing to my deep sense of peace to just be at home, still, enjoying the fact that summer is drawing to a close. As a child, I always felt that summers were long and I looked forward to the excitement of the fall when change is most evident. This summer too seemed long. And, although I know each day is to be savored, I find myself longingly looking forward to Labor Day and the changes of the fall.

My summer—like every summer should be—was filled with laughter and great memories. In retrospect, these memories eclipse most of the bad times. I met with an exuberant Doc Mary in June who had just returned from an oncology conference. She announced that it appears that this is the decade for making strides in colon cancer research. Even more importantly, she gave me the results of the treatments and my "tumors" were less than 50% of their original size. (Being the classic overachiever, I will admit that at first I did not greet this news enthusiastically—I wanted no less than 100% reduction! Patience, Lindy, patience.) The good news continued to roll in. Instead of having to have the grueling 12 treatments, she hopes that I'll be able to have only eight. Thus, I should be done the week before Labor Day. Then, we will begin a maintenance program which will hopefully keep the cancer in check. Apparently, with the marvels of

modern medicine, this can be done through vaccines or pills or I could join a test trial. Finally, Doc gave me leave to forego treatment for a month so that I could go to London to attend two meetings.

What I Did On My Summer Vacation A whole month without treatment, what a gift. It was as if Doc Mary had truly given me a summer vacation. Since I didn't know what this "maintenance program" would entail—that is, whether I would be on a low dose of chemo for the rest of my life and how it would make me feel—I thoroughly enjoyed each day away from treatment. I will admit to questions that lurked in the back of my mind. Was I being crazy to stop treatments for a month and would it allow the disease to become more entrenched in my body? Should I just get the treatments over and done with? Was I literally playing with my life? Although I consider myself an equal partner with Doc Mary and Team Smiley in my care, Doc Mary is the one with the "MD" after her name and I trust her implicitly. It feels as if every move she makes is carefully considered and weighed. Therefore, if she said I could go, it was good enough for me.

Even though I had two intense meetings to attend in London, to me it did not feel like work. As with the last time I had cancer and went to London, the primary issue was the same: designation of Particularly Sensitive Sea Areas. Wherein last time it was to revise the guidelines to designate such sites, this time it was actually to designate a particular place in the United States, the Papahānaumokuākea Marine National Monument or the area of the Northwestern Hawaiian Islands. These islands stretch 1,200 miles northwest of the populated Hawaiian Islands and are made up of an amazing coral reef ecosystem. The more we worked on this project, the more exciting it became.

Imagine, it is one of the last places on the planet where sharks keep the food chain in balance. Endangered monk seals and turtles inhabit the area and millions of seabirds make it their home. Since international shipping passes through this area and, because of the coral, navigation is hazardous, we were trying to adopt measures to protect it from damage. Unfortunately, some of my colleagues and friends and the Defense and State Departments were less than thrilled by NOAA's actions and we ended up in a protracted interagency squabble that ended a step before President Bush. Needless to say, once in London, the agencies came together and, in particular the U.S. Coast Guard, helped us get our measures passed.

In addition to Hawaii, there were many other issues to keep my interest. Coming directly from my Michigan roots and the zebra mussel, the issue of aquatic nuisance species in ships' ballast water has always fascinated me and the negotiations to try to resolve this issue continue. The Canadians had a proposal to protect my favorite clients, the North Atlantic right whale. Barbados had a paper that was developed at a workshop I ran to protect coral reefs from anchor damage and Ecuador needed additional measures to protect the Galapagos. I ended the meetings with a deep sense of gratitude for being able to help in a small way and I am so thankful that I have the job I do. It does make me laugh to think that at 46 years old I am probably considered one of the "old timers" at these meetings and yet, with the continuity of experience, comes the ability and responsibility to strive to help others, continue to learn and grow, and be better at the job.

I will admit that the best part of the trip to London was the people. Although my dear Roubs left for home leave in Mauritius soon after I got there, we had a couple of days together to chat. Joe and Paul threw open their arms and home to David and me.

We had many good dinners and chats, went to see the new Harry Potter movie, and Joe and I scavenged for the best price on the last Harry Potter novel. One of the most wonderful people I reconnected with was my dear friend, colleague, and mentor, Captain LaMeijer. This man has done more than anyone I know to make navigation safe and environmentally friendly around the world and I have missed him since his retirement. With his wonderful wife, we spoke of things near to the heart and that only come by living and loving others fully. At the first meeting I had my three dear friends Bry, Kathy "the mariner", and Mary to lean on and watch me to make sure that I was okay. There were also my wonderful colleagues, Jen and Derek, who kept me propped upright when tiredness washed over me, brought me cappuccinos and lunch when I had drafting to do, and were there to share the workload and celebrations.

Luckily, I had a week off between meetings. David came over and, wanting a relaxing and restful time, we went to Paris. Now, after reading this statement you may wonder whether the drugs have affected my mind! Well, it all depends on how you wear life. I remember one speaker once described one woman as wearing life as a long, flowing coat instead of wearing it as most of us do, tight as a girdle, trying to keep everything in control. We wore Paris as a long, flowing coat and had a blast. Of course, we walked a lot and went to my two favorite museums, the Quai D'Orsay and Musee Rodin. Even though I had lived in Paris as a college student, I had never been up to the top of the Eiffel Tower or on a river boat. Hand in hand, we laughingly engaged in these tourist attractions and explored the City. When things got overwhelming, we escaped to a garden with a bottle of wine, cheese, a baguette, and fruit. It was exactly what I needed, relaxing and restful.

Despite some initial qualms about taking this month off treatments, I will admit that it was exactly what my body needed. I went into treatment two days after returning. There was no question about my blood or whether the treatment would be given. And, with the jetlag and drugs, I slept a lot. When awake, I had the loving support and presence of Nesa and my adorable niece Haley. Even with the respite, the treatment was painful and, after having so much freedom, it almost felt like I had gotten my wings clipped and thus was rather discouraging. I handled it in the only way I know how, I gritted my teeth and focused on the end game: Labor Day.

Déjà vu All Over Again? Most of us in the cancer community spend time during our first journey through the cancer world obsessing about the reoccurrence of the disease and how to prevent it from occurring. Others, so I hear, don't even want to talk about this possibility or admit that it exists. Even so, I doubt any of us ever again treat life as a guarantee or with the same carefree attitude as before the disease. The question, however, that we cannot escape as we go through the seemingly endless stream and never-ending schedule of checkups is the attitude with which we are going to face this issue of reoccurrence. I had decided at the end of the last round of treatments that I was not going to face my checkups with fear and worry, but treat them as life affirming. I vowed to take each day as it came, come what may. Therefore, when Doc Mary delivered the unwanted news on April 9th that the disease had returned, I could only mechanically put one foot in front of the other. The "if" of possibility had been wiped out by certainty. Nevertheless, over these past seven treatments, this issue of reoccurrence has continued to fester in my subconscious.

I have decided that there are three issues involved: the physical issues, the medical issues, and the spiritual issues. With regard to the physical issues, one of you mentioned to me at the beginning of all of this that at least I knew what to expect. I grumpily had to admit that was true and, in some ways, it is. However, cancer tried to teach me the lesson the last time to expect the unexpected and, especially after the last five days, I learned once again that it—and its cure chemotherapy—have endless mean and humiliating tricks up their sleeves. The similarities include the routine of beginning treatment on Monday with the weight-watcher weigh in and other vital checks, the peeing in a cup, the battery of anti-nausea (throw up) drugs which cause me to sleep through the chemotherapy injections, and leaving with an umbilical cord attached to a whirring box that gives me injections of chemo every 15-20 seconds through Wednesday when I am literally jonesing to get to Doc Mary's to get the box removed. The drugs have also remained the same, although now all of them except the one in the box are given on Monday (which makes for a very long day). My level of Oxilplatin, which causes the terrible tingling in my feet and hands, had been elevated until I reacted badly and then it was reduced once, then again. Finally with regard to the drugs, although during the last treatment I had never met the Harry Potter brewmaster of my drugs, I now look forward to seeing spunky Michele each week, another invaluable member of Team Smiley.

The side effects continue. Unfortunately, the fire diarrhea and other bathroom issues are a constant concern and forcefully remind me to avoid all dairy products. Conversely from last time, these effects don't disappear after a week but to my dismay have been lasting a lot longer. Although I simply don't eat anything cold during treatment week because the Oxilplatin would make it feel as if my throat were

constricting, this effect and the tingling in my hands and feet seem to be far less severe. The latter may be a result of the reduction in the dose of Oxilplatin or because Doc Mary added a dose of calcium and magnesium to my mixture. During the last week, my hair has started to thin and it is disconcerting to find wisps of it clinging to my fingers when I wash my hair.

There have been two major physical differences. First, as I mentioned in my last email, I am faced almost daily with overwhelming tiredness. Thus, I haven't been swimming as I did the last time. With regard to work, I am amazed to think that I used to go into the office on the Thursday and Friday of chemo week. Now, if I work during treatments, I do so from home and even do so a couple of days during the off week. And, whenever I need to, it's simple: I nap! This tiredness seems to underscore that once you have been through chemotherapy—and no matter how strong and resilient you look or seem to be—your body is just not the same and, with reoccurrence, you don't just reset at the same point as you were when you started the first round of treatments. Let's face it, these drugs are strong; after all, I take or am given at least three or four anti-nausea drugs before they even start the injections of chemo. Thus, there is no way that you can be as resilient and deal with this onslaught as well as the first time through it all. I will admit, this fact bothers me especially as I look out to the future and know now with certainty that unless we find a maintenance regime that works, I will probably be faced with going through this all over again.

These past five days I have been introduced to pain that makes fire diarrhea seem like a cakewalk. Even though I never took pain pills after surgery, I had no compunction about taking them to combat this searing pain. As I finally realized that I needed help

from Doc Mary, tears ran uncontrollably down my face and every movement was affected. It turns out that it was caused by the fact that my seriously impaired immune system had allowed for the reoccurrence of a dormant chicken pox virus in the most private part of my anatomy. Now that I am through the worst of it and the day looks brighter, I can say that there is at least one positive aspects of this experience. It was never clear that I had had chicken pox, because my siblings had it when I was brought home from the hospital as a baby. I am certain now and smugly like to think that since I didn't get a severe case of it as a baby that even then my body was resilient against disease. It needs to be to face cancer!

The medical issues associated with reoccurrence are both predictive and preventative. During the first round of treatments, Doc Mary had told me that since I had Stage IV colon cancer that there was a significant risk of reoccurrence. Significant risk indeed! There were 17 months and 18 days between my last treatment of the first round and my first treatment of this second round. I asked Doc Mary if that meant that I had a particularly aggressive form of cancer. Having seen all varieties, she said that some cancers never go away and others don't come back. So I guess I'm in middle on this one.

The preventative issues are this so-called maintenance regime. I don't know yet what it entails. I have to say, however, that I wasn't very happy when I read two possible test trials in which I could participate. One seemed to require the periodic removal of lymph nodes and the other could have an effect on my brain. That put a damper on reading the other three that Doc Mary's researcher gave me. I also wonder how I am going to feel if I have to have a constant dose of chemo, no matter how low. How will it affect my life? You'll laugh, but I did ask Doc Mary whether that meant I'd never be able

to have a glass of wine or an ice cold beer on a hot day. She looked a little surprised but said no. Dad, always musing about things, wondered whether perhaps—depending on how a constant dose of chemo would affect me—it would be better simply to go through chemo treatments every 18 months, if necessary. Sitting here, still feeling wiped out from the latest surprising side effect, I can barely stand to contemplate that thought.

So, I'm in a waiting mode. I've two treatments since returning from London. Mom was here with me for the last one and my whirlwind and high energy sister, Katrina, came in from Montana to deliver her daughter to UVA to school. Dad comes in today and tomorrow we will begin the final round. I have a PET scan—yes, that lovely test where they inject me with radioactive dye and put me through a large scanning machine —on September 10th. That test will determine whether I have to face additional treatments before beginning the maintenance regime. I haven't felt any of the pangs in my lower tract that I did when it signaled the return of the disease, so I am very hopeful. I am also relying on the strength of my breathing and mantra practices as well as the great energy I receive everyday from all of you to bring me once again into the clear. Then, we'll deal with the maintenance regime. And, since there is no other way that I can think of to do it, I'll do it one step at a time.

Lastly and most importantly, are the spiritual issues. These issues start at the end of treatment with how you think about the possibility of reoccurrence and how, when facing a checkup, it will affect your spirit. Are you going to live in fear of the results and hold your breath until they come in? Well, you all know how I feel about the breath! It is the essence of life and, as I said before, I don't like to live my life in fear. After the first round, I tried to look at my checkups as life affirming and not let the possibility of

reoccurrence affect my spirit. I will do so again after this round of treatments, even though now we know that I have the type of cancer which was resilient under the onslaught of chemotherapy. I simply will have to trust that the maintenance regime will keep it in check. I am not going to live my life in the shadow of cancer, but rejoice in the fact that I had it twice and am still here to live life large, love unconditionally, and laugh as often as I can.

Another issue that came as a surprise to me was one that simply spilled out of me when David and I talked to Swami at Yogaville. When she asked what was in my heart, I told her that I simply could not figure out what the Universe was trying to teach me by forcing me to go through all of this again. While I don't buy into the thought that I have somehow now or in a past life done something that created bad karma so that I deserve to have cancer, I firmly believe that my life is about learning and growing. It was disheartening to think that somehow I had missed the lesson the first time around and therefore needed to do it again! The lovely Swami put my mind to rest. Each day our spirit grows and learns and therefore this time around I am in a different place than I was during the first round. As with anything anyone tells me, I have to go away and think about it, see if it makes sense to me and my value system, and then decide whether I agree with it or not. Swami's statement made a lot of sense to me. While I have not enjoyed having cancer one bit, it has helped me grow in ways that I could not have imagined. I am a better person than before cancer, I have more patience and am more forgiving. I see life more clearly and have become much more realistic about what I want to do. And then there is the most important thing which is that I have slowed down to

live more in the moment and with that has come the ability to love David, my family, and my wonderful friends with wonderful abandon.

The issue that I have still not come to grips with yet is what I can do to try to prevent the reoccurrence of the disease. I just have this deep sense that there must be something that I can do to change the fundamental environment of my body so that it is not conducive to the cancer. But how do I that? I can't and don't want to change my spirit and who I am—okay, I will admit that sometimes I can even annoy my own self, but generally I like who I am! So then, what? One thing that I consistently go back to is my diet. With the help of my wonderful nutritionist and friend, Cheryl Mirabella, I have made many improvements to my diet and I cook healthier foods now. There can, however, be further improvements in this area. With Cheryl's help and David's encouragement (he will eat anything and we love to cook together), this will be one thing that I will pursue.

The other thing that may fundamentally affect the environment of my body is the breath work that I was taught by Swami Shankradev and Jayne Stevenson. The breath is life and when doing this work, you can just feel the calming of the mind. Since there is a strong mind-body connection and since deeper breathing causes more oxygen in the blood, I have to believe that it will necessary cause a change in my body. Hmmmm, didn't this very principle help save the old man and the baby from the deadly disease in the Andromeda Strain? Well, notwithstanding, it is work I will continue.

Finally, the only other thing that may fundamentally affect my body is that if we live in harmony with our beliefs, then our bodies must feel more settled and calm. The problem is, however, that most of us get caught up in racing around and the trivialities of

the moment. We don't stop and check to see if how we are spending the majority of our time is actually consistent with what we say—and think---are the things in the world that are most important to us. I too am guilty of this and need to become more mindful of how I am literally *spending* my life.

The last spiritual issue associated with reoccurrence is the very real possibility of dying. While I was in London, my cousin Penny—who had fought breast cancer for 12 years—died. We grew up across the road from each other and all of us first cousins used to romp in the fields, catch pollywogs, and have our very own clubhouse of which I remember her being President. We hadn't talked in years and yet, a couple of months before she passed, she called me. I was so touched. Another gift of cancer, we were drawn together because of the disease. We shared the bad experiences but then moved quickly on to wonderful things that had happened in our lives as well as the important lessons we had learned. For her and for me too one of the most important things that cancer has underscored is the importance of family and loved ones. We recognized how hard it must be for them to stand there closely with us, trying to do all they can, but in the end helpless against the ravages of the disease. She said that the hardest thing of all was to reach the point that she had, a time when she had to ask her loved one, Ray, and her sister, Carlene who lived through so much with her, to let her go. She just couldn't face any more drugs, any more treatments. As I prepare to go home to Michigan to her funeral, I cannot even contemplate how hard that decision was for all involved. There may come a time when I too have to make that request of my family and friends, although I am not anywhere close to that yet! It is, however, a sobering realization and reminder of how to live life. And, in the words of Nesa, we don't know how much longer

I may have on this earth, but what we do know is that for whatever time remains, I am going to live life fully.

Conclusion So, I am actually looking forward to tomorrow's treatment, because I fervently hope it will be the last. Of course, if it turns out *not* to be the final one, then I'll take it in the same manner that has helped sustain me thus far, one step at a time and, as much as possible, with an upbeat attitude. I do so hope it is the last, because I am looking forward to a wonderful fall of visiting with dear friends, seeing my family and feeling great the entire time I am with them (!), and building my life with David. Life is wonderful and change—although I resisted it for years—is inevitable and a very welcome thing in my life!

Take care, live life large, love unconditionally, and laugh often,

Thanks for listening,

Lindy

2012 Addendum

Lovingly added by Lindy's husband and life puzzle-piece, David

Unedited last email correspondence to loving family and friends around the world.

September 7, 2009

Hi everyone! I hope this email finds you enjoying the last few days of summer and looking forward to the fall. I love this "in between" time of year. The late sounds of summer warn us to bask in the waning sunny days, the temperatures annoy us with their boomerang tendencies, and the gardens are releasing the last of their bounty. As for me, it is very much an "in between" time too, but not because of the pending season change. After having an absolutely wonderful beginning of the summer, we hit a bump in the road these past few weeks where I ended up in the hospital and I'm scheduled to go back in next week—being "in between" hospital visits is somewhere I never wanted to be, but well, that's where we are. We are taking it as we always do: looking forward with a lot of hope to the fall to come and, until then, taking each day one step at a time.

Hopscotch to Hospitals As many of you know, I have been getting chemo almost non-stop since January. It has been a tough year, because our quality of life definitely takes a dip during the chemo weeks. In July, Doc Mary wanted to see what was happening with the three tumors that we knew were there—one on the right hand side of my colon, one on the left hand side, and one on the liver. She didn't like what the CT scan showed. Unfortunately, instead of shrinking from the chemo, the tumors had grown. Being a fighter, Doc Mary then pored over my ever increasing file. She found that most of my tumors appeared on the outside of the major organs; apparently the cancer has not yet figured out how to invade them. Moreover, even though I have these three tumors, they are not that big. She therefore suggested that perhaps it was time to try a new strategy, which was to surgically remove the tumors. We therefore stopped chemo treatments (because if I were to get surgery, I could not have had Avastin—a blood thinner—for over month) and set up consultations with two surgical oncologists. One was Dr. Fraker at the University of Pennsylvania and the other was Dr. Weiser at Sloan-Kettering in New York.[22] With these appointments made, I was enjoying the end of the summer without chemo. Life was great.

Everything came to a screeching halt quite literally mid-August. My darling David was off on a trip to Germany when I began to notice cramps radiating down the left hand side of my leg. I thought about it and could not remember the last time I'd had a bowel movement. I don't know about you, but after getting through being a kid where bathroom issues are of great interest, I just don't pay attention to them! I monitored the cramps through Sunday, but continued my day by working out, doing some yard work, and just generally enjoying the day. By Monday, the cramps had increased in severity so that when one was happening, it literally took my breath away. I canceled a briefing I had scheduled at work and a massage. I must've sounded like I was in pain when

[22]One word to the wise for anyone ever facing this disease—you have to take responsibility for your own treatment and getting through to doctors, don't expect anyone to do it for you. I mistakenly relied on the scheduling person at Sloan to make my appointment, but somehow my records got lost for two weeks, then the doctor said that what I really needed was a medical oncologist (meaning he didn't understand the question that I had conveyed and hadn't looked at the over 8 pages of chemo that I'd been on), and therefore my appointment did not get scheduled until after almost a month after I initially made contact with them.

cancelling the massage, because at the time of my appointment Jette—the massage shop owner—knocked on the door. She tried to do her magic to move things and nothing worked. She then sat in the chair and basically told me that I could either let her take me to the hospital or get someone here to help me. I called Sarah and she came flying. After she was here only a short time, I started to throw up the laxative that I had taken. That was the sign, it was time to go to the hospital.

We went to Fairfax Hospital emergency room because it is just down the road from Doc Mary's and she is associated with it. I regretted that decision as the night wore on. After sitting there for 3 hours and Sarah making multiple pleas on my behalf for them to do something, she helped me hobble up to the desk where I told them that I was going to pass out, throw up, or cry unless they helped me. I immediately started to cry, so I guess they knew I wasn't kidding! Back in the ER, we waited a further two hours and 2-3 more throw ups before they did anything. They gave me two enemas, took an X-ray and CT scan, admitted me for the night and then, the next day, without doing anything further, sent me home.

I knew things weren't over when I left that hospital. Doc Mary by this time was in constant contact with me. By Thursday, she advised me to stop eating and come into the office to receive fluids. On Friday, my sister Trin came here after dropping her daughter off at school and David came home—I was so very glad to see both of them. Saturday passed in a haze as I tried to take another gut bomb laxative that did nothing but upset my system. Doc Mary and David were on the phone several times. On Sunday night, she called him and told him to take me to the emergency room at the University of Philadelphia so that I could see Dr. Fraker. Early Monday morning, we were in the ER where we were immediately checked into a bed and they started taking care of me. This is where the story takes a bit of a turn. I thought I was there to talk to Dr. Fraker about removing the tumors and yet his staff was obsessed about the blockage in my colon. Life threatening, you know. Huh, really?! That thought had just not occurred to me. My colon was apparently 3-4 times its normal size and they were very concerned about it rupturing. Conversations flew around about how they were going to deal with it and with each passing conversation, I grew more nervous and agitated. This was just not what I thought was going to happen and I hate surprises—especially when strapped to an IV in a hospital bed. And yet, that nasty little tumor on my left hand side had caused a severe blockage and changed the dynamics of what we expected was going to happen.

I saw Dr. Fraker on Tuesday. I immediately liked everything about him from his bedside manner, to his proficiency, to his steady hands. He said that he no longer did the kind of surgery for which Doc Mary had referred me to him, but that he had a colleague whom he'd worked with at National Institute of Health (NIH) who was located in Baltimore who was doing it. He called him and luckily for me, Dr. Alexander agreed to take me, blocked colon and all. We had to wait for a bed to open up in Baltimore for 24 hours and then I was on my way, yes in the back of an ambulance that felt very much like a martini shaker!

Dr. Alexander is located at the University of Baltimore Medical Center. So it too, like the University of Pennsylvania is a teaching hospital. For those of you who may not know what this means, let me give you a few clues. It is not uncommon to be woken up at 6:00 a.m. and look down at the end of your bed at 10 interns staring down at you. One of them, the chief resident, will ask a few questions, and then the group will swirl away. It is also not uncommon to be repeatedly checked over and checked in on by various young doctors. I rather like that—I feel like I have a team of exceptionally bright people pulling for me. The one thing I did check was that the nurses who were proposing to stick me with needles were not students!

The other thing I have to say before leaving this subject of hospitals in general is that truly hospitals are nowhere that you want to be to get healthy. First and foremost, there is the roommate problem. I continually drew the loudest and most obnoxious roommates both in Philly and in Baltimore. They would yell when they talked, even when it was the middle of the night. Second, you just can't sleep in a hospital. Someone is always coming to do something to you—whether take your blood pressure, your temperature, and your pulse or worse yet, your blood. Third, time passes so very slowly in a hospital and, I don't know why, it's difficult to read or really do anything. (We did play several rounds of euchre and Kings Corners!) The clock just stares at you from the wall, reminding you of all the things that you'd usually be doing at this time of day in your normal life. Finally, pain hangs in the air at hospitals and it is difficult to keep a happy, cheerful, and hopeful outlook in the face of such a ubiquitous feeling.

In the face of all these odds, I had two powerful weapons: David and Mom. I will admit that I called Mom and literally begged her to come. She arrived on Tuesday morning to join our little team; she's been a godsend for David and me. David is just sunshine himself. I don't know how he does it, but he would bounce into my room in the morning and I knew that everything was going to be okay. Both he and Mom have a great steadying, upbeat attitude and, especially early in the week when we didn't have a clue what was happening, I really needed it. One scene I will never forget is as I was being wheeled in from the ambulance, I could see David and Mom waiting for me outside my room with big grins. They had just met "Tony". Apparently, the University of Maryland has robots that deliver drugs; they talk, ride elevators, and basically are hard workers. We giggled about that and I told Dr. Alexander that I didn't want to come to his floor unless he had a robot (luckily he does).

The plan for the way ahead slowly revealed itself to us. First, they had to deal with the blockage. Dr. Alexander wasted no time getting that fixed. I was whisked away to surgery on Thursday and a stent put in place (a small metal ring that gradually increases to a certain size, thus enhancing the size of the colon). Over the next two days, stuff continued to pour out of me and I went from having constipation to the other extreme. Second, Dr. Alexander and his team talked to me about the surgical oncology that they proposed for me. To my shock, it's an 8-10 hour surgery, with 3 days recuperation in the intermediary care unit, then a further week to two weeks in a private room in the hospital. The fancy name for it is hyperthermic interperitoneal chemotherapy (HIPEC). David and some of my other friends have done some research on it, but as for me, I know just

enough to make the decision that is the best way forward. Basically, they will open me up and do exploratory surgery, looking for and removing any sign of cancer tumors and cells. Then for 90 minutes, they will run chemo which has been heated up to at least 104 degrees through my abdominal cavity to further kill any cancer. Finally, after I get out of the hospital, I will return to Doc Mary's care for follow up chemo. I had to admit, Dr. Alexander was really giving this his all. While it won't mean that I will never have cancer again (most unfortunately), hopefully it will get rid of it for some time.

Initially, we thought that I would simply stay in the hospital and get the surgery done the next week. However, Dr. Alexander, being very cautious, wanted me to be in the best possible shape. Since I hadn't eaten for 9 days, he thought it best that I go home for 10 days and regain my strength. I was delighted—going home! I did not want to stay in that hospital doing nothing but waiting, especially over the weekend.

It has been great to be home. To my surprise, I didn't bounce back and live an active life these past days. Instead, I have slept a lot and had quite a few bathroom issues (darn disease!). Mom and David have tempted me with all different types of food but none seem appetizing because they immediately result in colon issues. Notwithstanding all this sitting around (which you know drives me crazy), I must admit, I haven't been worrying about the pending surgery. Worrying doesn't get you anywhere. I am also one of those people that once a decision is made, then you just march through it, no matter how painful the experience may be. The only way to get through these things is moment by moment and with the help of family and friends.

Wyoming Wonder So enough about that! The real story of my summer vacation is our wonderful time in Grand Teton National Park. With family and a few close friends, David and I got married on June 26. We had a week of activities prior to the ceremony of hiking, white and flat water rafting, dinners at a cowboy chuckwagon and the Mangy Moose Saloon, going to the rodeo (something I'll never do again!), and spending time hanging out at the campground. Yes, that's right about 17 of us camped while others stayed in hotels in nearby Jackson. I couldn't have asked for the weather to be better or there to be more wildlife. Mom, Nesa, my niece Haley, and I went on a 3 day backpacking adventure before everyone arrived and, in the course of 10 minutes, we saw a deer, a moose and her baby, and a huge cinnamon bear. Most people saw moose, buffalo, and elk. Many who went to Yellowstone saw griz (I saw my first!) and one couple saw wolf bothering elk. So very cool.

The wedding ceremony itself was small and intimate which is just what we wanted. I didn't feel like I was on a stage with people watching—instead there was an almost palpable circle of love embracing us. David and I both wore cowboy boots—mine were red! The mountains in their splendor created a beautiful backdrop. Even though I had worked in the Tetons for six years, I had never been to the place where we got married. It was an old abandoned ranch that had been previously owned by the first female rancher in the valley. It was about a quarter of mile off the road, down a path that meandered across a small wooden bridge with the swift flowing Cottonwood Creek underneath it. The meadow was filled with bright yellow flowers. We couldn't have asked for a more

beautiful setting. And then there was the weather. The valley hadn't had one nice day before we arrived and yet most of the week we were there the sun shone and there was little rain (except for the weekend before people arrived, where Lake Johnson filled my brother's tent). The morning of the ceremony, we woke to rain; however, it broke about midday and we started the ceremony with the clouds hanging around the peaks. About three-quarters of the way through it, just as Bry (who introduced us) was talking, the heavens opened up, the wind picked up, and the rains came. We crowded onto a porch that had a huge overhang and finished there. People got wet, for sure, and it definitely added drama to the day!

With David, my family, and wonderful friends by my side, I could not be facing this next step on my journey better prepared and being more loved. I so very much thank Sarah, David, and Mom for the nights that they spent propped up in a chair, trying to sleep through a night at the hospital with me. Thank you all as always for listening and for your support. It truly does get me through the hard times. Throughout this next week and especially on 9/9/09 (how much more of an auspicious date can you get than that?! Especially for us yoginis!), take a moment to give the loved ones standing next to you a big hug and make them laugh. That's what life is all about, isn't it?

Until I see you again, live life large, laugh often and love unconditionally. Love and hugs, Lindy

List of Major Environmental Treaties, Rules, and Other Initiatives that Lindy Johnson Played a Key Role in Shaping

1) London Ocean Dumping Convention: Lindy was among a small group of people who played a key role in shaping amendments that led to a global decision to prohibit the dumping of all radioactive wastes and numerous other wastes previously disposed of at sea. She was also a pioneer in bringing wide-spread attention to a precautionary approach to marine protection which, through her personal efforts, was incorporated into the London Protocol and became a central point of the international debate concerning marine pollution policy.

2) Cartagena Convention / Land-Based Pollution: Lindy served as one of the primary legal drafters for this unprecedented international agreement that sets forth quantitative effluent standards for specific land-based discharges into the Wider Caribbean Basin. This Agreement was adopted in 1999, was recently ratified by the United States, and will soon enter-into force.

3) International Ballast Water Treaty: Adopted in 2004 after some 10 years of debate at the International Maritime Organization, Lindy was a tireless advocate for development of biologically-based international standards regulating the discharge of marine ballast water. Ballast water is recognized as a primary vector for transferring invasive aquatic species around the globe. Lindy was one of only a handful of people who successfully argued for biology-based standards (versus technology-based standards). Her success in convincing both the U.S. government and numerous other countries on this point, led to a fundamental and radical shift in the structure of the treaty.

4) Global Antifouling Treaty: Adopted in 2001, this treaty radically changed practices in the global maritime fleet as the treaty banned the use of tributyltin (TBT) coatings for use on ships. TBT is recognized as one of the most persistent and toxic chemicals ever introduced by man. Used on ship's hulls, the product dominated the market due to its effectiveness in keeping ship's hulls clean. The effort to bring about a global ban was highly contentious. Also important was the fact that this negotiation permanently shifted the political landscape at the IMO as it set in place new entry-into-force provisions that were previously considered impossible to modify. As a result, environmental treaties developed in London can no longer be blocked by a small group of flag states that control most of the world's merchant tonnage. Lindy served as the primary counsel to the U.S. delegation in these negotiations and was indispensable to the effort.

5) International Air Pollution Standards / MARPOL Annex VI: In the 1990s and early years of the past decade, research demonstrated that ships contributed significantly to air pollution in North America, Europe, and areas across the globe. Negotiations led to an initial agreement in 1997 and then again to major amendments in 2008 that will dramatically reduce air emissions from ships. Once again, Lindy played the key role in drafting the international regulations. She was specifically requested by EPA to lead drafting efforts at the IMO in London. In 2007, during negotiations in Berlin, Lindy was asked to lead a drafting group to compile the first legal draft of the treaty amendments. Once again the discussion was highly contentious and many of the countries were seriously opposed to many, if not all of the standards being debated. Some 48 hours later, Lindy emerged with a draft text that after another year of debate,

now stands as one of the most stringent environmental agreements to emerge from the International Maritime Organization in its history.

6) Establishment of Particularly Sensitive Sea Area (PSSA) Guidelines at the IMO: Lindy was the central driving force in development of marine protected area guidelines at the IMO. She became the recognized "go-to" person for countries around the world seeking to designate marine protected areas. As Lindy would walk through a meeting at IMO, countless people would grab her by the elbow to seek advice on how to proceed with a given action they were considering with the aim of protecting a specific area of the ocean. One person once remarked to me "My God, Lindy is a rock star! She is unbelievable." Indeed, she was an incredibly persuasive force, playing a significant role in helping countries with the designation of numerous marine protected areas around the world.

7) Designation of the Florida Keys / Dry Tortugas PSSA: Lindy led an effort in the United States and at the International Maritime Organization to designate the Florida Keys and Dry Tortugas as a Particularly Sensitive Sea Area (PSSA). The designation in 2002 serves to protect corals by establishing no anchoring areas in the Tortugas and is designed to reduce the threat of spills from vessel collisions and contribute to safer, more efficient shipping. Billy Causey, Superintendent of the Florida Keys National Marine Sanctuary, described Lindy's role in achieving the designation as "extraordinary." I doubt you would find anyone who would disagree.

8) Designation of the Galapagos Archipelago PSSA: Recognized as the world's foremost expert in marine protected area regulation, Lindy provided extensive assistance to Ecuador as that country prepared a proposal for designation of the Galapagos Archipelago PSSA. The area was approved in 2005.

9) Papahänaumokuäkea Marine National Monument PSSA: On April 3, 2008 the Papahänaumokuäkea Marine National Monument in the Northwestern Hawaiian Islands was designated as a Particularly Sensitive Sea Area by the International Maritime Organization. As might be expected, designation of the area was spearheaded by Lindy. The area encompasses a 1,200 mile stretch of coral islands, seamounts, banks, and shoals; is home to more than 7,000 marine species and contains 4,500 square miles of coral reefs. Lindy's effort to establish the area as a PSSA also laid the foundation for subsequent international recognition of the area's unique cultural value. In 2010, the United Nations added the area to the U.N. Educational, Scientific, and Cultural Organization (UNESCO) World Heritage List.

10) Development of the Ship Strike Reduction Provisions for Protection of the North Atlantic Right Whale domestically and internationally: In 1997 Lindy attended the first meeting to address the threat of ship strikes for right whales and offered to help. She led the charge on getting the first educational measure through the International Maritime Organization in 1998 for mandatory ship reporting and followed that up with measures for two right whale areas in Canada, three more in the US, as well as guiding a suite of domestic measures to slow ships down to give right whales a greater chance. Because of Lindy's efforts, right whales are now afforded more protection from ship strikes in the waters off eastern Canada and the United States than ever before.

There are many events that demonstrate Lindy's impact on international marine policy, but Moe Brown offered a couple examples that provide some insight into the impact of Lindy's work at the IMO. The first was when the delegate for Panama, Captain Ian

Finley, took the microphone in London following a statement by Lindy, where he stated that it was "The right time to do the right thing for the right whale." On another occasion, the head of the IMO Sub-Committee on the Safety of Navigation, Kees Polderman, came up to Moe Brown at a meeting to ask "Are we (IMO) doing enough for right whales?" It was Lindy who brought right whales to the attention of IMO and made unprecedented progress in right whale protection.

11) Authored *Coastal State Regulation of International Shipping:* Even though Lindy worked long hours week after week and year after year in meeting the demands of her work at NOAA, the U.S. Government more broadly, and the IMO, she found the time to author one of the most respected books outlining coastal state authority in regulating marine activities and protecting the marine environment. The book is standard reading for attorneys examining coastal state practice and the roles and legal responsibilities outlined in the 1982 United Nations Convention on the Law of the Sea.

12) Other Accomplishments: An objective and comprehensive list of "Other Accomplishments" for Lindy would be immense. It includes work in the protection of the Arctic, her leadership in revising international standards for carriage of radioactive materials on board ships, countless legal and policy developments under the MARPOL Treaty, and numerous efforts that have resulted in better protections for whales and other cetaceans, among others. The many awards she has received for her distinguished service and will continue to receive are a testament to her incredible professional productivity and success. More importantly, anyone who ever met or worked with Lindy quickly understood that a rare, tireless, enthusiastic, and wonderful person had entered their life.

13) 2011 Posthumous Award, International Maritime Organization, London, England

The Council of the International Maritime Organization in it's 106th Session, by acclamation, awarded the **International Maritime Prize for 2010** to the late Ms Lindy S. Johnson, who was nominated by the Government of the United States of America, in recognition of the outstanding contribution Lindy had made to the work of the IMO and the maritime community as a whole over many years. The prize was accepted on her behalf by her husband, David Beddoe, July 11, 2011, IMO on the Thames, London, England. The procedings and presentations were captured by the IMO and are available by request of the IMO.

Appendix 1

Doc Mary's Methodology

Doc Mary

1. Doc Mary's philosophy and goal is that all of her patients—no matter what stage of cancer they have—should be able to continue to live their normal lives, even while getting chemotherapy treatments.

2. If there were any signs of trouble (*e.g.*, vomiting!), Doc addresses it immediately and thus I felt like she was trying to keep my body as healthy as possible to fight the disease.

3. Doc employs methods that will enable her patients to best withstand the side effects of the chemotherapy. For instance, when it became clear that the chemo drugs made me queasy, Doc adjusted the order in which I was given the anti-nausea and chemo drugs, the amount of time that the injections were given, and prescribed additional anti-nausea drugs. I was on decadron which was used to help prevent nausea and caused me to maintain—or even gain—weight.

4. At the beginning of each treatment, the technicians would ask me if I had made any changes in the vitamins or drugs I was taking so that Doc Mary could accurately determine what was going on and how best to treat me.

5. Doc Mary stays informed about the cutting edge of cancer and other medical research and would, depending on each individual's situation, use whatever drugs best suited to a person's needs. As the research developed, she was not afraid to adjust a person's drugs. For instance, I was on the blood thinner Coumadin so that clots would not form because of my medi-port. On day, after I was complaining about how many drugs I had to take, she took me off it because research had been released stating that it was unnecessary.

6. Doc Mary is incredibly patient and spends the time to address all of a patient's questions—and believe me, I had a lot of questions! If she didn't know the answer, she would do the research and get back to me on it.

The Staff

7. Everyone that works for Doc Mary is friendly, compassionate, courteous, and highly efficient. They are not stand-offish or distant and not afraid of becoming involved in a patient's life. By this very act of caring, the staff supports the healing of their patients' spirits as well as their physical being.

8. The staff goes out of their way to make people comfortable in extremely uncomfortable and distressful circumstances.

9. While it doesn't lessen the effect, the nurses provide an honest assessment when something is going to hurt and commiserate with the patient.

10. It is difficult to keep track of the myriad of doctors' appointments, procedures, and instructions that must be followed. Doc Mary's staff thus facilitates these things for her patients. In particular, they remind patients of specific dates and ensure that they have appointments scheduled. Moreover, they work with patients in scheduling appointments at a time that works best for them and call to remind them when they are scheduled.

The Office

11. It was always such a relief to talk to a person instead of an answering machine when calling the office, no matter what time of day.

12. Since Doc Mary is in a practice with several other doctors, they take turns being on call. Therefore, whenever I called the office because I needed to speak to a doctor, one was always available and, after speaking to the receptionist, a doctor always called back in under two minutes.

13. This may seem minor in the scheme of things, but it is important since cancer patients spend a lot of time in doctors' offices: Doc Mary's office has the current and up-to-date magazines in the waiting room. In other doctors' offices, I noticed that the magazines were at least two years old!

14. Another aspect of the office that made a difference to me was whether the pictures, mobiles, and décor had been purchased along with the office space or whether there was more of a personal touch. Patients (or perhaps should I just say this patient) look for ways to connect with their doctors and the décor is one way

to make patients feel connected and comfortable. One doctor's office that I had to visit had an ocean motif. I took comfort from this fact and was therefore disappointed when I asked him whether he enjoyed the oceans and liked to sail (there were sailboat mobiles hanging in every examination room). When I asked this question, he appeared to notice the mobiles for the first time!

Sandy, Maria, Kristen, and Triscilla, wearing the warm smiles with which they greet me whenever I visit Doc Mary's office.

Appendix 2

Success

Ralph Waldo Emerson

To laugh often and much;

to win the respect of intelligent people and the affection of children

To earn the appreciation of honest critics and endure the betrayal of false friends;

to appreciate beauty, to find the best in others;

To leave the world a bit better, whether by a healthy child, a garden patch or a redeemed social condition;

to know even one life has breathed easier because you have lived.

This is to have succeeded.

Desert Solitaire

Edward Abbey
(with my minor amendments)

One final bit of advice: Do not burn yourselves out. Be as I am—a reluctant enthusiast—a part-time crusader, a half-hearted fanatic. Save the other half of yourselves and your lives for leisure and adventure. It is not enough to fight for the land [and oceans]; it is even more important to enjoy [them]. While you can. While [they are] still here. So get out there and…mess around with your friends, ramble out yonder and explore the forests [and the oceans], encounter the grizzly [and dolphins], climb the mountains, bag the peaks, [dive the ocean depths], run the rivers, breathe deep of that yet sweet and lucid air, [walk on a long sandy, desolate beach listening to the crashing waves.] sit quietly for awhile and contemplate the precious stillness, that lovely, mysterious and awesome space. Enjoy yourselves, keep your brain in your head and your head firmly attached to the body, the body active and alive, and I promise you this one sweet victory over your enemies, over those desk-bound people with their hearts in a safe deposit box and their eyes hypnotized by desk calculators. I promise you this: you will outlive the bastards.

Excerpt from "The Zahir"
As a thanks for my friends

Paulo Coelho

A warrior of light knows that he has much to be grateful for.

He was helped in his struggle by the angels, celestial forces placed each thing in its place, thus allowing him to give of his best. That is why, at sunset, he kneels and gives thanks for the Protective Cloak surrounding him.

His companions say: 'He's so lucky!' But he knows that 'luck' is knowing to look around him and to see where his friends are, because it was through their words that the angels were able to make themselves heard.

Appendix 3

Useful Books

It's Not About the Bike: My Journey Back to Life, Lance Armstrong (2001)
Love, Medicine and Miracles: Lessons Learned about Self-healing from a Surgeon's Experience with Exceptional Patients, Bernie Siegal (1990)
Man's Search for Meaning, Vikto E. Frankl (1946)
Asana Pranayama Mudra Bandha, Swami Satyananda Saraswati (1996)
One Bite at a Time: Nourishing Recipes for Cancer Survivors and Their Friends, Rebecca Katz (2004)
Feed Your Soul: A Cookbook that Nourishes Body, Mind and Spirit, George Fowler and Jeff Lehr (1994)
The Alchemist, Paulo Coelho (1993)
The Tao of Healing: Meditations for Body and Spirit, Haven Trevino (1993)
Unexpected Recoveries: Seven Steps to Healing Body, Mind, and Soul When Serious Illness Strikes, Tom Monte (2005)

Indispensable Things to Have

Bag Balm
Wet Wipes
Sound proof earphones
Good music
Good books
Good humor
Good attitude
Great family and friends
Gloves to leave by the refrigerator
Room temperature bottled water
Wide-brim hat and sun block
A book in which to keep notes and questions